University of Alberta

Child-Headed Households: Children Living the Consequences of HIV/AIDS in Western Uganda

by

Franziska Miriam Satzinger ©

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Abstract

This study explored the situation of child-headed households in Kabarole District, Uganda. The main aims of the study were to determine the number of child-headed households in the district and to document the experiences and needs of these children. An estimated 2127 households (2% of ali households) in Kabarole District are child-headed. Sources of income are extremely scarce, and the children's vulnerability to illness, low educational attainment and increased psychological stress is heightened as a result of their circumstances. Basic needs such as scholastic materials and fees, food, clothing, and bedding are grossly lacking. Conflict with community and extended family over land, persistent fears of theft and abuse, and illness among siblings are sources of considerable anxiety. Government and non-governmental organizations urgently need to strengthen their response to mitigate the impact of HIV/AIDS on these children. Community leaders must raise awareness about the issue and motivate communities to become involved.

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Dedicated to the memory of Gitao

and to all of the children who have been affected by this devastating epidemic.

You have inspired me to devote my life to this incredible part of the world.

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Chapter One: Introduction

The impact of HIV/AIDS in Africa is often illustrated by accounts of high morbidity and mortality among the productive segment of the population and the loss for the local economy and functioning of society that ensues (Ntozi & Mukiza-Gapere, 1995). The detrimental effect of the disease on some twelve million children in sub-Saharan Africa who have become orphaned because of this epidemic is less frequently addressed (UNICEF, 2004).

The presence of orphaned children in sub-Saharan Africa is not new, many children having been orphaned over the years because of high rates of maternal mortality (Madhavan, 2004). The effect of HIV/AIDS in increasing this phenomenon to catastrophic proportions is substantial, however (Foster & Williamson, 2000). In Uganda, children who are orphaned by the death of their parents from HIV/AIDS often come under the care of their extended family within the community, which allows them to maintain highly-valued cultural traditions of family and community ties (Nyamukapa & Gregson, 2005; Danzinger, 1994). Some children, however, lack familial ties within the community. Either they have recently migrated to the area, their relatives have also died (Muwonge, 2002), or they lack someone who can care for them. In such situations, these children may form a child-headed household, within which usually the oldest child in the family assumes the responsibility of caring for the younger siblings.

It is this subset of orphaned children in Uganda's western Kabarole District that is addressed in this study. The paucity of research on child-headed households urges for a needs assessment of these children as well as the identification of formal and informal support available to them. The circumstances of children who are orphaned by the HIV/AIDS epidemic and consequently live in child-headed households, as well as the possible impact this may have on the future of their

society, are addressed. This study explores the relationship between the children's needs and the resources available to them, and uses this to inform recommendations for strengthening and extending the existing support structures available to these children.

1.1 Purpose of the study

This study sought to assess the prevalence of child-headed households in Uganda's western Kabarole District and to explore the plight of children as they cope with their lives as child heads of households. It aimed to document the impact of this epidemic on child-headed households in order to guide and intensify efforts to address this problem.

1.1.1 Research questions

Three questions guided the study: 1. How many child-headed households exist in Kabarole District? 2. What are the experiences and needs of adolescents (aged 13 – 18) who become heads of households and care for their siblings? 3. What formal and informal resources are available and required to support these adolescents?

1.1.2 Background

Uganda's HIV/AIDS epidemic has undergone considerable changes since its beginnings in the early 1980s. Initially, the epidemic added considerable detriment to a population already afflicted by several decades of civil strife, at one time resulting in the highest rates of HIV infection in sub-Saharan Africa. The peak of the epidemic in the early nineties (1990 – 1992) saw HIV prevalence rates among pregnant women as high as 30% in major urban centres (Kilian, 2002). Under the strengthened leadership of President Yoweri Museveni who came to power in 1986, strategic government action and non-government initiatives resulted in a visible decline in infection rates and effectively decreased stigmatization and ignorance of the disease. Programmes were developed to increase awareness and education, initiate behavioural changes, and provide

essential services and support for those seeking assistance in preventing themselves from becoming infected. In particular, Kabarole District has benefited from population-based interventions of this kind, often focusing prevention messages to youth and young adults (Kilian, 2002). In 1990, key representatives from the district implemented an AIDS Control Program to tackle the issue of HIV/AIDS and its social and economic impacts on the society (Kipp, 2002). Despite these valuable efforts, the long-term consequences the epidemic continues to have on children orphaned by the disease are considerable.

1.2 Literature review

A literature search was conducted using the following databases and search engines for years 1990 – 2006: PubMed, NEOS Library Consortium Catalogue, Elsevier Science Direct, and Scholar Google. Key words searched included the following: child-headed households, orphan, child/ren, Uganda, Kabarole, Africa, child health, health, extended family, HIV, and AIDS. Cross-referencing of the initial literature review provided additional references for this study.

1.2.1 Orphanhood in Uganda

The situation of children orphaned by the HIV/AIDS epidemic in Uganda and other parts of Africa is now a well-studied phenomenon. One of the most important contributions to knowledge about orphaned children in this region comes from Susan Hunter who, in the late 1980s and early 1990s, was instrumental in bringing the impact of HIV/AIDS on the children in Uganda's Rakai District to the surface. Conceptualizing the problem of orphaned children as "a window on the potential for massive social breakdown and dislocation in sub-Saharan Africa resulting from high AIDS-related mortality," she expressed her concerns about the future of societies impacted by severe AIDS epidemics (Hunter, 1990, p 681). Her studies offered important initial insight into the plight of orphaned children and their families, and set in motion a widespread interest in the topic as she challenged AIDS researchers to take up the task of addressing this phenomenon.

In discussing orphanhood at length, the variability in what defines an orphaned child must briefly be addressed. Most often, definitions of orphaned children distinguish between double orphans, maternal orphans, paternal orphans, and total orphans. UNICEF (2004) defines a double orphan as a child under 18 years of age who has lost both his/her mother and father. A maternal orphan is defined as a child under the age of 18 whose mother, and possibly father, has died. For statistical purposes, this definition includes double orphans. A paternal orphan is a child under 18 years whose father, and possibly mother, has died. Again, this definition includes double orphans. A total orphan is also defined as a child under 18 who has lost both parents, yet is distinct from a double orphan in that "the total number of orphans is equal to the sum of maternal orphans and paternal orphans, minus double orphans (because they are counted in both the maternal and paternal categories)" (UNICEF, 2004).

Children who lose both parents invariably suffer greatly from this loss (UNICEF, 2004), yet the death of only one parent can also have a dramatic effect on the lives of those who remain in the family. A father's death likely means the loss of the main breadwinner for the family, affecting the remaining children's and mother's capacity to sustain themselves. A mother's death is detrimental to the family because of her instrumental role in raising the children and providing an important source of labour in subsistence farming and other sustenance measures.

The difficulty in clarifying this difference wellbeing between those who lose their fathers versus those who lose their mothers is, in fact, attributable to a number of factors. Widowers are more likely than widows to remarry after their spouse's death, perhaps benefiting the children as they again have two guardians looking after their wellbeing (Kongwa et al, 1991), yet fewer women are opting to marry widowers, leaving the fathers to care for their children on their own (Ntozi and Mukiza-Gapere, 1995). Surviving fathers may be less inclined to look after their children upon the death of the children's mother, leaving many children to be cared for by other relatives. UNICEF (2004) observes that less than one-third of

maternal orphans live with their biological fathers, suggesting that they may suffer significantly upon the death of their mother. Clearly, all affected children suffer from the loss of their parents. The substantial burden carried by those who are orphaned by both parents and have no one to take care of them is even more traumatic.

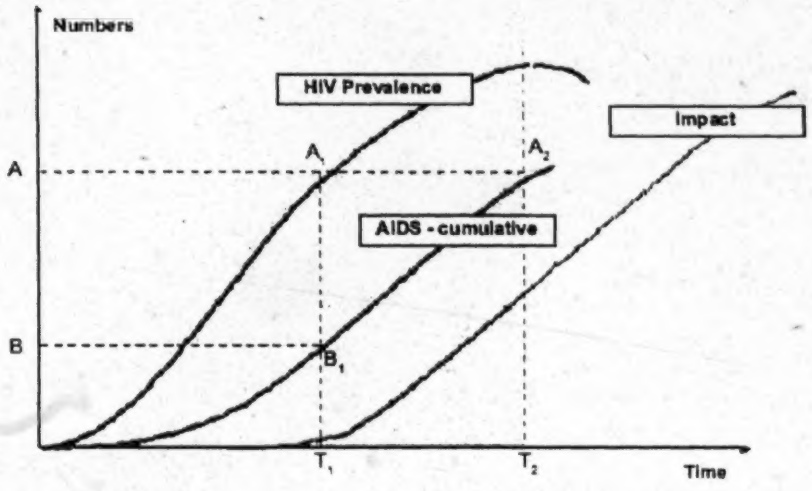
1.2.2 Trends in Orphanhood

Uganda's population of orphaned children is estimated at two million, constituting almost eight percent of the country's population (UNAIDS, 2006). Despite the apparent decline in HIV prevalence in the country since the mid-1990s (UNAIDS & WHO, 2005; Green et al, 2002), the number of orphaned children is expected to increase in the coming years (UNICEF, 2004). Predictions have also been made that child-headed households will be seen in increasing numbers over the coming years.

> As the numbers of orphaned children multiply, it is likely that there will be increasing numbers of child-headed households; they will become less transient, existing for longer periods; and household heads will be younger. (Foster et al, 1997, p 166)

This can be explained largely by the observation that trends in orphaned children and child-headed households do not occur simultaneously with trends in HIV prevalence, the latter of which are marked by reasonably long incubation periods and have recently benefited from medical interventions that can delay death by several years. Peaks in HIV prevalence precede peaks in the severe impacts left in the disease's wake, meaning that high numbers of orphaned children and/or child-headed households follow high HIV prevalence trends, rather than occurring concurrently with them (Smart, 2003).

Figure 1.2.2. Trends in HIV prevalence and impact



Source: Smart (2003).

This suggests that, although Uganda boasts a remarkable record in combating the AIDS epidemic and has experienced a measurable decline in the number of people infected with the disease (Stoneburger & Low-Beer, 2004), the number of orphaned children has not yet followed the same downward trend as HIV prevalence and orphanhood will likely continue to have a detrimental effect on society for years to come.

1.2.3 Role of the extended family in orphan care

The contribution of Hunter's work to the study of orphaned children is now among many others who have contributed to the field of research on orphaned children in sub-Saharan Africa. What is common to the majority of these works is their focus primarily on the situation of orphaned children that end up living with members of their extended family. Much of the work neglects what is now developing as an increasingly common circumstance of households headed by child siblings.

Studies consistently highlight the strength of the extended family and its important role in orphan care. Customarily, orphaned children are taken in by an

uncle or an aunt or, increasingly, a grandmother. A study carried out by Ntozi in six Ugandan districts in the early 1990s notes that,

> Almost all orphans are cared for by their parents and members of the extended family, indicating that the role of the family as a protector is still strong. (Ntozi, 1997, p 38)

Ntozi (1997) further points out that, despite a lack of assistance from external sources, the extended family has made a sincere effort to cope with the increasing numbers of orphaned children. Culturally, it is preferred that orphans remain within their communities so that they can be properly socialized into the customs and culture of their families (Danzinger, 1994). It is believed that children can avoid losing their homes and their land inheritance if they find assistance within their extended families. By remaining within their communities the children reduce the vulnerability of the community's capacity to regenerate itself in the future (Danzinger, 1994).

The tradition of the extended family as a valuable support system is so strong that children's homes or orphanages, although existing in larger towns and cities in Uganda, are quite rare and largely seen as a last resort (UNICEF, 2004; Nyamukapa & Gregson, 2005; Danzinger, 1994). Institutional responses of this nature are believed to contribute to the social breakdown of family structures and are more often than not difficult to maintain over the long term. Hunter suggests that institutional responses, such as children's homes, are "a culturally-destructive, last ditch non-solution injurious to children's welfare" (1990, p 684). Because institutional responses are held in low regard, many children whose parents die of AIDS often end up living with relatives in the same community or on the streets of larger towns and cities. In the patrilineal system dominant in this region, children belong to their father's families and consequently often live with their father's family upon his death (Nyambedha et al, 2003). If the mother is deceased, children will more often be cared for by a grandparent than by their surviving father (Ntozi, 1997). Given the importance of the extended family structure as a safety net for children orphaned by HIV/AIDS, the research focus

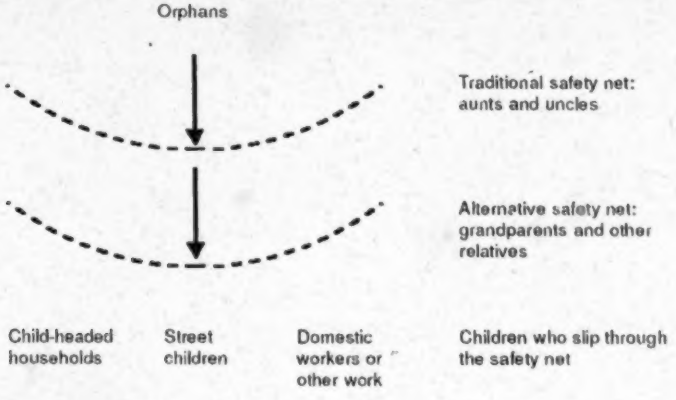
on orphaned children who are looked after by their extended family members is thus not surprising. This research is influenced by a strong tradition of families and communities carrying the burden of care for children who lose their parents prematurely (Nyamukapa & Gregson, 2005).

1.2.4 Breakdown of extended family

Over the years the AIDS epidemic in Uganda has developed into a disaster of such magnitude that the extended family, who has traditionally assumed the role of looking after orphaned children, has become overwhelmed. Studies have pointed to the immense impact of this epidemic on the traditional family structure (Ankrah, 1993). The burden of the almost two million orphaned children in Uganda on the extended family is spurring a breakdown in traditional family and social systems (Foster, 1998). With increasing numbers of orphaned children, decreasing numbers of available caregivers, and a weakening extended family, the traditional social support system is coming under considerable stress (Nyamukapa & Gregson, 2005). The growing number of children orphaned by AIDS is outstripping the capacity of traditional coping mechanisms of these communities, and – at times – siblings are split up among various fostering homes, effectively worsening the chances of the children to overcome the loss of their parents (Muwonge, 2002).

Given the widespread effect of the AIDS epidemic the traditional support system of the extended family is struggling to maintain its structural integrity and is showing evidence of weakening, leaving children to be cared for by elderly grandparents or their own siblings (Foster, 1998). Foster presents a simple yet descriptive diagram of the change in the traditional safety net provided by the extended family.

Figure 1.2.4. Model of the extended family safety net for orphans in Africa


Orphans
Traditional safety net: aunts and uncles
Alternative safety net: grandparents and other relatives
Child-headed households
Street children
Domestic workers or other work
Children who slip through the safety net

Source: Foster (2000)

This model succinctly shows the extended family's decreasing capacity to cope with the overwhelming numbers of orphaned children that are occurring simultaneously with numerous deaths among those who would customarily take responsibility for looking after these children.

Foster and his colleagues point to a number of other important factors that they deem responsible for the breakdown of the traditional family support structure. Using Zimbabwe as an example, they identify "changes such as labour migration, the cash economy, demographic change, formal education and Westernization" which have taken place in sub-Saharan African countries and have had the effect of weakening the extended family" (Foster et al, 1997, p 156). Their observations offer insight into the potential causes for this change in traditional coping mechanisms:

> Labour migration and urbanization have led to a reduction in the frequency of contact with relatives and encouraged social and economic dependence; possessions are perceived as personal property and no longer belong to the extended family. Increased life expectancy and family size mean it is now not possible for the extended family of three or four generations to reside together; the diminishing availability of land makes it difficult for large families to be economically independent through subsistence agriculture. Education about social values

> is likely to be obtained from schools and interactions of children with their peers rather than through traditional mechanisms, which has lessened the ability of older people to exert social control over the younger generation. Brideprice is nowadays often a cash payment earned by the husband-to-be, rather than cattle and other possessions raised by members of his extended family; thus marriage itself has become more a contract between two individuals leading to weaker links between and within extended families. (Foster, et al, 1997, p 156)

Despite these dramatic changes in the structure of traditional support and the appearance of child-headed households these authors emphasize that the extended family is still the most effective support system for orphaned children in sub-Saharan Africa. This illustrates "the strength, resilience, and adaptability of extended family coping mechanisms" (Foster et al, 1997, p 157). The extended families' efforts to visit their orphaned relatives in child-headed households, and to provide them with material and emotional support whenever possible are, for Foster and his colleagues, indicative of adaptation to the changing structure of society.

> These [efforts] are indications that in many cases, households headed by children or adolescents are a new expression of the extended family's coping mechanism rather than the result of children slipping through the extended family safety net. (Foster et al, 1997, p 163)

They further point out that despite having relatives nearby who could look after them, children may find themselves left in child-headed households upon their parents' deaths because they have demonstrated a capacity to care for their siblings during the time the parents were ill and are thus seen as capable of continuing to do so after their death.

It has been suggested that this weakening of the traditional safety net for orphaned children is due to the increasingly limited financial resources of extended family members who are required to use what resources they have to pay for medical

care of their own family members who may be infected with HIV (Ntozi et al, 1999). Foster notes that that "the extended family is not a social sponge with an infinite capacity to soak up orphans" (Foster, 2000, p 55), yet he and his colleagues urge caution when assuming that the relatively new phenomenon of child-headed households is due solely to the breakdown of the extended family. Pointing to the dearth of literature on the topic of child-headed households prior to their own study, they warn,

> Though it is often assumed that the presence of these [child-headed] households in communities implies that extended family methods of support have broken down, this assumption has not been validated since there have been no previous studies of child-headed households. (Foster et al, 1997, p 155-156)

At the same time, however, Seeley and Kajura urge caution in generalizing or overemphasizing the importance of the role of the extended family in this society.

> Blanket statements about the role of the extended family in Africa as a safety net need to be questioned and assumptions that the extended family will be ready and able to assist [AIDS] sick members, treated with caution. (Seeley & Kajura, 1993, p 120)

Although this statement relates specifically to the role of the extended family in supporting those afflicted with AIDS in south-west Uganda it might also apply to the situation of orphaned children. Highlighting the unique nature of the AIDS epidemic, which occurs over a period of several years, Seeley and Kajura (1993) outline the common over-exploitation of the extended family network as a critical support structure, noting that the extended family is often of limited assistance in the care of those suffering from the disease and that the burden often falls on the shoulders of individuals who must cope with limited assistance.

1.2.5 Child-headed households

Literature focusing specifically on child-headed households is sparse and limited almost exclusively to one researcher. Geoff Foster, Director of the Family AIDS Caring Trust in Mutare and Consultant Paediatrician at Mutare Provincial Hospital, Zimbabwe, has studied orphanhood in sub-Saharan Africa and more recently began to examine the phenomenon of child-headed households throughout the region. Together with his colleagues, he identified several pre-conditions for the establishment of child-headed households and examined the role of the extended family in assisting such children (Foster et al, 1997).

Foster observes the change in the societal framework in sub-Saharan Africa since the onset of HIV/AIDS. He highlights that the phrase, "there is no such thing as an orphan in Africa," once the catch phrase exemplifying the strength of the extended family safety net, is no longer applicable to the current state of these societies (Foster, 2000, p 56). In a work about the development of child-headed households, he and his colleagues propose a number of predisposing factors that lead to the establishment of child-headed households. These include,

> Rapid increase in the number of parental deaths; death of one or both parents; reluctance of relatives to foster orphans; lack of contact of relatives with children; death or sickness of a relative; presence of adolescents or older children able to care for younger children; preference of children to live in child-headed households; last wish of dying parent; death of single mother; and inheritance of residence by surviving children. (Foster et al, 1997, p 162-163)

The undeniable role of AIDS in the increasing prevalence of child-headed households is also emphasized.

> Although AIDS is only one of several factors leading to the changes being observed in traditional patterns of child care... it is undoubtedly the main factor predisposing to the establishment of child- or adolescent-headed households. (Foster et al, 1997, p 162)

Foster, although recognizing other factors that have contributed to the breakdown of the extended family structure, highlights the unique effect of AIDS on this process.

> Weakening of the extended family as a safety net mechanism for the care of orphans was occurring even prior to the impact of AIDS on communities. The AIDS epidemic has accelerated these changes and has led to new coping practices. (Foster, 2000, p 59)

Apart from Foster, others who acknowledge the existence of child-headed households in Uganda have generally downplayed the extent to which they exist, emphasizing instead the valuable role of the extended family in providing a safety net for orphaned children. Examining the effect of AIDS on family and household structure in Uganda, Ntozi and Zirimenya illustrate this point.

> Households headed by children are rare, indicating the major role played by the extended family in the upbringing of orphans, especially those who lose both parents from AIDS. (Ntozi & Zirimenya, 1999, p 209)

This is representative of the majority of literature that, although not explicitly focusing on child-headed households, recognizes their existence and deems them an uncommon circumstance.

Foster has made valuable contributions to our understanding of child-headed households, describing their development and highlighting the urgency of their needs. Literature looking specifically at the situation of child-headed households in western Uganda nevertheless remains scarce. Children taking on the position of the head of the household when no member of the extended family is available or willing to take over this task, exhibit one of the most severe negative social impacts of HIV/AIDS on families and the society. The dynamics within a household inevitably change upon the death of the children's parents, as the oldest child takes on responsibilities that are usually assigned only to adult caregivers or parents. Yet children begin to experience the effects of orphanhood well before

the death of their parents as they take on increasing responsibilities in the home, doing household chores and possibly even being responsible for bringing income into the home when their parents are too ill to work. At the same time, they are confronted with the emotional and mental burden that accompanies their parents' illness.

Being part of a child-headed household significantly jeopardizes the health and wellbeing of the children as they lack fundamental resources for living and become highly susceptible to illness. Healthcare in sub-Saharan Africa largely relies on women and mothers as primary healthcare workers and often trains them in this role. Consequently, the loss of this caregiver can be detrimental to the health of children as they are unaware of and untrained about important health measures such as proper nutrition and simple treatments such as oral rehydration therapies (Foster, 1998). In addition, children may be less likely than their mother to correctly identify an illness, which increases the likelihood that it will go unnoticed and progress to a stage that is difficult to treat. Lack of information and education about identifying symptoms and various treatments place children in child-headed households at increased risk of poor health (Foster, 1998).

In addition to the immediate consequences of living in a child-headed household, the future of the society will also see significant consequences. Children grow up without important familial, traditional, cultural, and social knowledge that parents impart to their children as they develop. The foundation upon which the society rests is threatened as traditional systems are disrupted and widespread changes in customs ensue.

1.2.6 Becoming a child-headed household

Despite the detrimental effects of living in a child-headed household, Plan International suggests that such households come into existence partly by the children's own choice (Plan Finland, 2005). The organization proposes three primary reasons that account for the formation of child-headed households: 1. The

extended family's inability to cope with the extra burden of their orphaned relatives; 2. The children's tendency to feel less vulnerable to abuse, exploitation, and neglect if they remain by themselves rather than living with extended family members; and 3. The children's desire to remain together with each other in a setting that is familiar to them. The second and third of these reasons, Plan argues, "imply an element of choice by the children" which represents "a new coping mechanism in response to the impact of HIV/AIDS" (Plan Finland, 2005, p1). This reflects the realities faced by the children, their extended families, and their communities as the impact of the epidemic continues to affect the population.

Similarly, Foster and his colleagues propose that, for some children, living in a child-headed household is preferred over living with a relative or other adult.

> In some cases, siblings in a family may choose to form child- or adolescent-headed households. The children may desire to stay together as a family group rather than be split up between various relatives, or wish to stay living at their own residence in familiar surroundings, rather than change school, friends, home and neighbourhood. They may resist attempts of relatives to foster them in the relative's household, fearing maltreatment or because the relative only agreess to foster young siblings. Orphaned children may be concerned about losing their inheritance rights to property and land if they are fostered... Children may actively choose to stay living together in their own household rather than relocate to a poor, reluctant or abusive relative's home. (Foster et al, 1997, p 164)

This is not to trivialize the challenges encountered through living in a child-headed household, yet rather provides a contextual understanding of the variety of factors involved in the establishment of child-headed households.

1.2.7 Succession Planning

Succession Planning, whereby families make an effort to minimize the potential negative effects of the parents' deaths on the children, can be part of an overall strategy to address the problem of child-headed households in Uganda. Plan

International, an organization that has made an effort to address the phenomenon of child-headed households in Uganda for the past twelve years, uses Succession Planning as a component of a three-step response to the impact of HIV/AIDS on children. The three step plan also includes HIV/AIDS awareness and behaviour change, and the provision of antiretroviral (ARV) treatment to infected parents (Plan Finland, 2005). Despite efforts to address the root causes of child-headed households, they still come into existence and efforts must be made to minimize the negative consequences that result after their parents' deaths. Succession Planning is suggested as a means of addressing this concern. Its main purpose is to mitigate the negative effects that result from the parents' deaths through the creation of a will and a memory book before the parents die.

In the most basic form, Succession Planning involves two important processes that must occur prior to the parents' deaths. First, a will should be created that clearly entitles the remaining children to the land left behind by their parents. Second, a memory book should be created by the parents with their children. Gilborn and her colleagues offer a succinct description of the main proponents of their proposed intervention.

> The primary target groups for succession planning are HIV-positive parents, their children, and standby guardians. [Succession Planning] includes counselling for HIV-positive parents on serostatus disclosure to children through memory books, support to appoint future 'stanby' guardians, legal literacy and will writing, assistance with school fees and supplies for children, income-generation training and seed money, and community sensitization (with some variation in components by study site). (Gilbert et al, 2001, p 5)

The potential for such an intervention to minimize the negative consequences of the parents' deaths and to assist the children as they cope with the changes occurring during this fragile time is encouraging.

1.2.8 Education

Throughout Uganda, school fees for secondary school are prohibitive for many families. Uganda's policy of Universal Primary Education (UPE), introduced by President Yoweri Museveni in 1996 as a component of the government's White Paper on Education (Ministry of Education and Sports, 2004), initially indicated that up to four children per family could access primary education free of charge (Aguti, 2002). The plan was to eventually allow all children access to primary education. While this policy effectively increased primary school enrolment in Uganda from 2.5 million children in 1996 to 6.8 million children in the year 2000 (Uganda Communications Commission, 2006), the system remains far from perfect. Required scholastic materials such as books, pens, uniforms, shoes, and various incidental fees still prohibit many children of primary school age, especially those living in child-headed households where resources are particularly scarce, from attending school.

The absence of an adult breadwinner in child-headed households makes access to education for these children extremely difficult. For many child-headed households, even accessing primary school can be difficult. The effects of missing out on education during childhood go beyond the loss of valuable knowledge and skills. Gilborn explains,

> Poorer access to school puts orphans at an educational and economic disadvantage but also represents a threat to their psychological well-being. Being in school, having contact with a teacher and other children, and having the proper school supplies are crucial to a child's sense of well-being and belonging. Having to drop out of school is a crushing blow. (Gilborn, 2002, p 14)

1.3 Methodology

1.3.1 Study design

This study used a combination of non-experimental, cross-sectional, quantitative and non-experimental qualitative methods. A survey questionnaire and semi-structured in-depth interviews were used. These methods enabled the researcher to 1) discover the scope of the phenomenon of child-headed households in Kabarole District; 2) identify the support structures available to and required for child-headed households; and 3) explore the situations of children living in child-headed households as expressed by the head of each household.

The impact of the epidemic on orphaned children living in child-headed households was assessed by enumerating the number of child-headed households in Kabarole District, observing the living arrangements of these young families, and carrying out a needs assessment of the children. This not only assisted in assessing the extent of this problem throughout the district, but also brought the issue to the forefront of local consciousness, possibly having the intended effect of encouraging community leaders to take action to address it (Hunter, 1990). A needs assessment documented the extent to which basic necessities such as school fees, health services, clothing, food, and safe water are available to child-headed households. Existing formal (governmental and non-governmental organizations) and informal (familial and community) sources of support and resources were identified, eliciting the specific needs of ongoing projects and support mechanisms. Based on this evaluation, methods for supporting and strengthening existing coping mechanisms, as well as possible intervention strategies, are recommended.

Data collection took place from September 8 to December 20, 2005 in Fort Portal Municipality and throughout Kabarole District, Uganda. Survey questionnaires were completed throughout the district, and semi-structured face-to-face interviews were carried out in the town of Fort Portal and its surrounding area.

1.3.2 Quantitative survey questionnaire

A 19-question survey was conducted with 178 leaders at the village level. This questionnaire was intended to gather information regarding the numbers of households affected by the death of both parents from HIV/AIDS, the recent trends in these numbers, and some of the social implications of HIV/AIDS as perceived by these leaders. The community perceptions and social dimension of child-headed households were also investigated through this format. In addition, the survey inquired about existing support services for children in these situations. On average, this questionnaire required approximately 25 minutes of the respondent's time.

Translation and Pre-testing of Survey Questionnaire

The survey questionnaire was initially developed during the research proposal stage prior to the researcher's departure to Uganda. Upon arrival in Fort Portal, local experts in public health were consulted about the cultural acceptability of the questions in the survey and small changes based on the experts' recommendations were made to the questionnaire. The survey questionnaire was then translated to the local language (Rutooro). Linguistic reliability was tested by a second individual who translated the Rutooro version of the questionnaire back into English. The new English version was then compared with the original English version. Differences between the two English versions were identified and corrected in the Rutooro.

The survey questionnaire was pre-tested with the intended target group to ascertain their comprehension as well as the acceptability of the questions. Three randomly selected respondents within Fort Portal Municipality were interviewed as part of the pilot process. Together with the research assistants who were present at these first three interviews, the researcher made slight revisions to the questionnaire. Additional coded responses were added to one of the questions, another question was taken out of the questionnaire as it had not been understood by any of the respondents participating in the pilot, a third question was omitted

because of its apparent redundancy, and minimal changes in the Rutooro translation and spelling were made throughout the questionnaire to suit the research assistants' comfort with the form of speech used.

Throughout the research process, expertise in research content and methodology was provided to the researcher by the following: Walter Kipp (International Health and HIV/AIDS), Duncan Saunders (International Health and Epidemiology), Lory Laing (Social Sciences), Peter Rothe (Qualitative Research Methods), and Tom Rubaale (Research Implementation).

1.3.3 Qualitative in-depth interviews

Twenty child-headed households were selected for in-depth interviews to constitute the qualitative component of the study. For the purposes of this study, the term "child-headed household" is defined using the framework provided by Foster and his colleagues.

> A household is one or more people who share cooking and eating arrangements. The household head is the person primarily responsible for the day-to-day running of the household, including child care, breadwinning and household supervision… A child is a person under 18 years old. (Foster et al, 1997, p 158)

A child-headed household is thus a household headed by a child 18 years of age or younger. This is a simplification and digression from more restrictive definitions that are used by other researchers to delineate child-headed households. Others define a child-headed households as

> A household where the children are double orphans (i.e. both parents have died) and is headed by a child that is recognised as being: independent; responsible for providing leadership and making major decisions in the running of the household; responsible, along with other children, for feeding and maintaining the household; [and] caring for younger siblings and adopting de facto adult / parent roles. (Plan Finland, 2005, p3)

While the details of this definition provide insight into some of the responsibilities characteristic of those carried by child heads of households, they are not required for the purposes of this study.

In almost all (18 of the 20) of the identified households, the oldest child was interviewed. In two homes the second-oldest child was interviewed because the oldest child was unavailable. These semi-structured interviews were conducted by the principal investigator with the assistance of a local interpreter. All sessions took place in or around the children's homes, where the respondent felt it was most suitable.

Each interview lasted approximately sixty minutes, with the exception of those interviews that were conducted predominantly in English, which lasted approximately forty minutes. The respondents were asked about their educational status, financial situation, sources of food, and basic household necessities. Psychosocial aspects of their situations were discussed, and the children's relationships with their extended families and communities were explored. Existing sources of support on which the children currently rely were identified.

Preliminary data analysis of these interviews commenced while onsite in Fort Portal. This included a continuous record of the researcher's reflections and observations arising during the research period and the identification of preliminary themes arising from the interview sessions. The remainder of the data analysis took place in early 2006, upon the researcher's return to Canada from Uganda. More focused interpretations of the interviews ultimately led to recommendations for a variety of interventions.

1.3.4 Study sample

Kabarole District is headed by an elected official at the level of Local Council 5 (LC5). This LC5 resides over two counties and one municipality at the level of LC4, each of which consists of three to seven sub-counties headed by elected

officials at the LC3 level. These LC3s are responsible for liaising between the smaller divisions that fall within their jurisdiction, the three to six parishes that are headed by an LC2, and the LC4s and LC5 of Kabarole District. Each parish contains anywhere from five to 18 zones or villages, headed by a Local Council 1 Chairperson (hereafter LC1). The task of the LC1 is to represent the local community and to implement initiatives at the grassroots level. This decentralized structure is intended to enable problems at the local level to be relayed upward to higher levels of LCs until they can be resolved by someone in a sufficiently authoritative position. Similarly, initiatives planned at the District level can, at least in theory, be relayed down these levels of Local Councils until they reach the zone or village level (hereafter zone), where they can be implemented.

Altogether, Kabarole District consists of 593 zones. A list of these zones was obtained from publicly available government sources in Fort Portal. Using Excel software, a random sample of 30 percent of the 593 zones in the district was generated. Because the LC1 residing over a zone changes over time, the list of zones includes only the name of each zone, not the name of the acting LC1. Efforts were then made to identify and interview this sample of 178 LC1s.

Some LC1s were not available at the time of the interviewer's visit. In those instances, the villagers were asked to inform the LC1 of the interviewer's visit and, if possible, arrange a meeting for another day. In only a few instances was it apparent that the intended LC1 would never be available for participation in this study. In that case an alternate respondent, such as the zone's Vice-Chairperson or the Secretary, was sought. Reasons for the LC1s' unavailability included the following: the LC1 had a) died and not yet been replaced; b) moved to the capital city, Kampala; c) felt that the Vice-Chairperson of his/her zone was better informed about orphaned children and suggested that we look for this alternative (one instance); or d) the LC1 was very ill and unable to participate.
Qualitative data was collected through 20 in-depth interviews in homes with adolescents (aged 13 – 18 years) who have lost their parents to HIV/AIDS.

Participants were selected through the identification of households by village leaders and directors of NGOs familiar with the area. Thorough interviews eliciting themes of importance to the subjects in 20 households provide a descriptive, qualitative illustration of the situations of these children.

Informal discussions with a number of directors of local NGOs also took place in Fort Portal. In these one-on-one meetings, general concerns about orphaned children, child-headed households, extended families, social support networks, official support, sponsorship, as well as the preliminary research findings were discussed with the NGO representative. Although their input is not explicitly outlined here, it was a valuable means of providing context for the research findings.

Subject inclusion and exclusion criteria

In order to be considered for participation in the in-depth interviews, respondents in child-headed households needed to be between 13 and 18 years of age. Respondents over the age of 18 were excluded as they do not fit this study's definition of child-headed households. (Those between 18 and 24 years of age would be considered adolescent-headed households). Children below 13 years of age were excluded from the study. Younger children would likely have more difficulty in understanding the interview questions. In addition, consideration of the emotional impact of participating in an interview of such a personal nature influenced this decision to limit the inclusion criteria for child-headed households respondents. It should nevertheless be noted that during the search for child-headed households for the purpose of interviewing, three households headed by children as young as ten years old were reported as available for participation in the study.

Nobody over the age of 18 could reside in the homes that were included in the study. Participants were included if an adult regularly came to visit the children or

cooked for them at times, but not if that adult stayed overnight in the same house with them for any considerable length of time.

Only those child-headed households where at least one parent had died of HIV/AIDS-related causes were included. Ascertaining this precise cause of death is logistically difficult, and the emotional impact the children may experience through investigating such a topic needed to be considered. The individuals making the initial contact with each home were thus relied upon for establishing the accuracy of this description for the researcher. Documentation or proof other than the informant's word that the children had lost at least one of their parents to HIV/AIDS was not required. Because of the high likelihood that most of the child-headed households are HIV/AIDS-related, this was not a particularly limiting factor for the study.

1.3.5 Ethical considerations

Age of children interviewed

Studies involving human research subjects as participants by necessity require informed consent prior to their involvement in the research (Berg, 2004). This is complicated when potential participants are considered incompetent to make an informed choice about their participation in a study. Children generally fall into this category, and provisions to ensure their safety are strongly encouraged. Most commonly, it is recommended that consent is given by the parent on behalf of the child (Shenk & Williamson, 2005).

By definition, however, children in child-headed households lack parents who could make such a decision for them and sign on their behalf. Because of this, the researcher proposed having local social workers attend each interview with children in child-headed households and asking them to sign on the child's behalf, yet on the recommendation of the University of Alberta's Health Research Ethics Board, Panel B, (HREB) this was not done. The HREB argued that children who are the heads of child-headed households make innumerable important decisions

about their lives and those of their siblings on a daily basis and, as such, are competent to sign on their own behalf.

Approval of the study

The study was approved by the University of Alberta's Department of Public Health Sciences; the University of Alberta's HREB; the National Council for Science and Technology in Kampala, Uganda; the District Director of Health Services in Kabarole District; and the LC5 Chairperson of Kabarole District.

Recruitment and informed consent

Each LC1 was told of the nature and purpose of the study before any commitment to participate was requested. An information letter was read and discussed and questions were immediately addressed. Specifics regarding the consent form were explained, and informed consent for inclusion in the study was requested. This included the consent to availability for follow-up should it be required by the researcher.

Because official records of child-headed households in Kabarole District do not exist, community leaders familiar with the region and the community identified the child-headed households that were used for interviewing purposes. Participants were selected if they met the inclusion criteria and demonstrated a willingness to participate in the study. In each case, the community leader made the first contact with the potential subjects and provided them with information about the study. With the child's agreement, an appointment to meet with the researcher and the interpreter was made. Upon meeting the child, the researcher and/or interpreter thoroughly explained the purpose of the study. An information letter was read and discussed until the respondent's understanding of the nature of the study and their involvement as research participants could be established. The consent form was thoroughly reviewed and, upon clarifying any questions or concerns, signed by the respondent, the interpreter, and the researcher.

The information letters and consent forms for both components of the study were available in both English and Rutooro. Illiterate participants had these forms read to them and provided a thumb print in the space of their signature.

Privacy and anonymity

The privacy of the subjects was protected by referencing respondents' names by number as data were collected. These are being used in lieu of the participants' names in this report and all other works that may follow. No names will be given in any reports, presentations or final documents that ensue from the study. The researcher is keeping a record of the name-number associations but will not disclose this information to anyone other than the co-investigator. The principal investigator and the co-investigator are the only persons with access to confidential data now and in the future. The data collected in the study will be locked in a filing cabinet for five years after the completion of the research, after which time it will be destroyed.

Possible adverse effects

No adverse physical effects were expected to result from this research. It was anticipated that emotional distress may arise during the interviewing process in child-headed households as some of the questions that were asked elicited sensitive information from participants. Both the researcher and the interpreter are trained, to varying levels, in counselling methods and were able to provide immediate support and comfort to children who expressed sadness or other emotions during the interview. Respondents were reminded that they did not need to answer any question they did not want to answer and that they were free to withdraw from the interview at any time.

1.3.6 Data collection

Research team training

Upon arrival in Fort Portal, two research assistants and one interpreter were hired to assist with data collection. The principal investigator thoroughly discussed the

project purpose and methods with the research team and concerns regarding data collection, recording and reporting were addressed. Assistants were fluent in both English and Rutooro and had some research experience.

Prior to commencing data collection, the principal investigator conducted several practice sessions with each research assistant, both individually and collectively, to ensure comprehension of the research methodology and content, as well as to increase their comfort level with the task at hand. Misunderstandings and confusion that arose on the first days of interviews with LC1s were cleared up immediately. The quality of the data collection was controlled through daily meetings during which the researchers thoroughly examined each questionnaire completed that day and addressed any inaccuracies or questions that arose. In one instance, a research assistant was asked to return to the LC1 he had interviewed in order to clarify a response that had been given.

Data recording

Responses provided by the LC1s were recorded on paper by the researcher and/or the research assistant. All interviews with child heads of households were audiorecorded and transcribed verbatim. Participants were advised of this procedure and consent for doing so was obtained prior to commencing any interviews. The researcher transcribed all sections of the interviews that occurred in English, including her own words, those of the interpreter, and those of the respondent. Local professionals transcribed and translated the Rutooro sections of the interviews. For analysis purposes, field notes taken during the interviews were used to supplement the transcriptions when necessary. They are being treated according to the same rules of anonymity and confidentiality as the remainder of the interview data collected.

Data analysis - Quantitative

Within 72 hours of each interview, the researcher conducted preliminary data analysis. Information from the LC1 survey questionnaires was recorded in Access

software while onsite in Fort Portal and preliminary findings were generated. This process enabled the researcher to identify potential questions or responses in the interviews that necessitated further probing or investigation.
To facilitate thorough analysis of the quantitative findings upon return to Canada, the data was transferred from Access to SPPS and Excel. This enabled the researcher to generate results using descriptive and bivariate analyses.

Data analysis - Qualitative

During the initial stage of data analysis while onsite in Fort Portal, dominant themes were identified. Comprehensive analysis of the data was carried out upon return to the University of Alberta, from January to April, 2006. The researcher's own transcriptions of the English components of the in-depth interviews as well as the translator's transcription of the Rutooro spoken during the interviews were used for this purpose. Analysis was conducted both manually and with the use of the qualitative data analysis software, XSight.

Initially, all transcripts were reviewed in order to obtain a general impression of potentially important themes in the data. Each transcript was then individually examined using XSight. This involved sorting each comment made by the respondent into categories. As the categories developed and expanded, themes were grouped together based on commonalities and over-arching concepts. All 20 respondents' transcripts were examined in this way. The XSight data was then transferred to Excel, where spreadsheets consisting of themes and supplemented with sub-themes, comments, and the respondents' quotes were developed. These were thoroughly reviewed and revised, until the researcher felt the data had been exhausted. These Excel spreadsheets were then used to inform the qualitative data analysis presented in this report. Where necessary, the original transcripts were again consulted in order to determine the precise context of quotes being used.

Chapter Two: Results – Quantitative

In the following, LC1s' responses to the questions asked in the survey questionnaire are presented. Unless otherwise indicated, all percentages given in this section are based on a sample size of 178.

2.1 Sample population

Fourteen female and 164 male village leaders participated in the quantitative study, including fifteen LC1 Vice-Chairpersons, one respondent LC1 Secretary, and 162 LC1 Chairpersons, all of which are hereafter referred to as LC1s. The 20 zones located within Fort Portal Municipality are considered urban and the remaining 158 zones are considered rural. Officially some of these rural zones may be considered semi-urban but for the sake of simplicity a distinction between semi-urban and urban is not made here.

Many LC1s surveyed in this study have been the Chairperson of their zone for a considerable length of time. Over half (53%) of LC1 respondents reported having been the Chairperson of their zone for more than nine years. Seven percent had held this position for six to eight years, 37% had been the Chairperson in that zone for three to five years, and only three percent had been in that role for less than two years.

2.2 Magnitude of orphanhood and child-headed households

2.2.1 Zone populations

Respondents were asked to provide estimates of their zone's population such that proportionate approximations of the orphan prevalence could be made.

Table 2.2.1. Median zone populations in project area

Median	500
Minimum	105
Maximum	7400
Sum (N = 176)	127860
IQR	342.5 – 746.5

Table 2.2.1 shows that the combined populations of the zones interviewed was 127 860, with a median village population of 500. These estimates are reasonably accurate given that 30 percent of all zones in the district were surveyed and this figure represents close to one-third (26%) of its overall population of 497 422 (Kabarole District Information Portal, 2006).

2.2.2 Orphan definition

Because of variations in the definition of orphaned children, LC1 respondents were asked to provide their own understanding of the term 'orphaned child'.

Figure 2.2.2. LC1s' definition of orphaned child

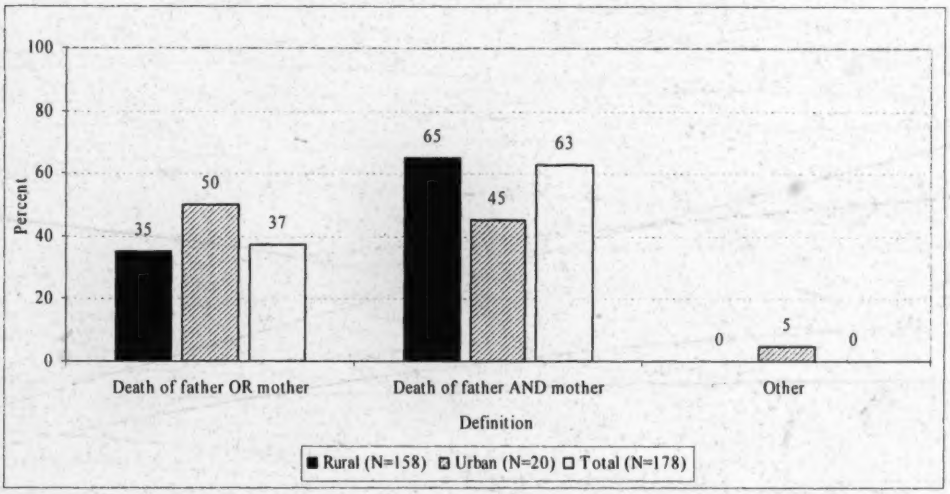


Figure 2.2.2 shows that respondents overwhelmingly defined an orphan as a double orphan (63%), a child whose father *and* mother has died, although variation between rural and urban respondents in how this was defined is evident.

Rural respondents predominantly considered an orphan as a child who has lost both parents (65%), and urban respondents defined it as a child whose father *or* mother has died (50%).

Estimates of the number of orphaned children according to these definitions are shown in Table 2.2.2.

Table 2.2.2. Estimates of orphaned children per zone in Kabarole District

Median	56
Minimum	0
Maximum	400
Sum	13112
IQR	30 – 100

The 13112 orphaned children reported by the respondents represent approximately ten percent of the overall population reported. Based on the definitions of an orphaned child given above, it can be inferred that two-thirds of orphaned children (approximately 47 orphaned children per village) in Kabarole District are total orphans, while the remaining third (approximately 27 orphans per village) are children who have lost either a mother or a father.

2.2.3 Number of child-headed households

LC1s participating in the survey questionnaire were asked "In total, how many households in your village do you estimate are headed by orphaned children of age 18 years or younger?"

Table 2.2.3. Estimates of child-headed households and AIDS-related child-headed households per zone in Kabarole District

	Child-Headed Households	AIDS-related Child-Headed Households
Median	6	5
Minimum	0	0
Maximum	40	30
Sum	1419	1055
IQR	3 – 10	2 – 10

The values presented in Table 2.2.3 are equivalent to a total of 4727 child-headed households when taken in relation to the overall district population. The 2002 National Census for Uganda estimates the population of Kabarole District at 494 422 with an average household size of 4.6 (Kabarole District Information Portal, 2006), indicating there are approximately 107 483 households in the district. This suggests that child-headed households constitute over four percent of the overall number of households in the district.

Respondents were also asked, "How many of these households you have just mentioned consist of children who have lost their parents to HIV/AIDS?" In total, they reported that 1055, or 74% of the 1419 child-headed households, were attributable to HIV/AIDS. This is not surprising, and may even be an underestimate, given that AIDS is now the leading cause of death among the adult population in Uganda (Ntozi, 2004) and that the present orphan crisis is due in large part to the concurrent AIDS crisis (Bicego et al, 2003).

2.2.4 Validation process

To account for potential over-reporting of orphaned children and child-headed households estimates that may occur as respondents anticipate future benefits to the community, a validation procedure was developed. Follow-up visits were carried out with 46 randomly-selected zones (excluding those who had reported zero child-headed households). During this follow-up visit, LC1s were asked to identify all the households initially reported in the survey questionnaire. A discrepancy between the number of households initially reported and those that could be identified during the follow-up was discovered.

Figure 2.2.4. Reported vs. identified numbers of child-headed households in 46 zones

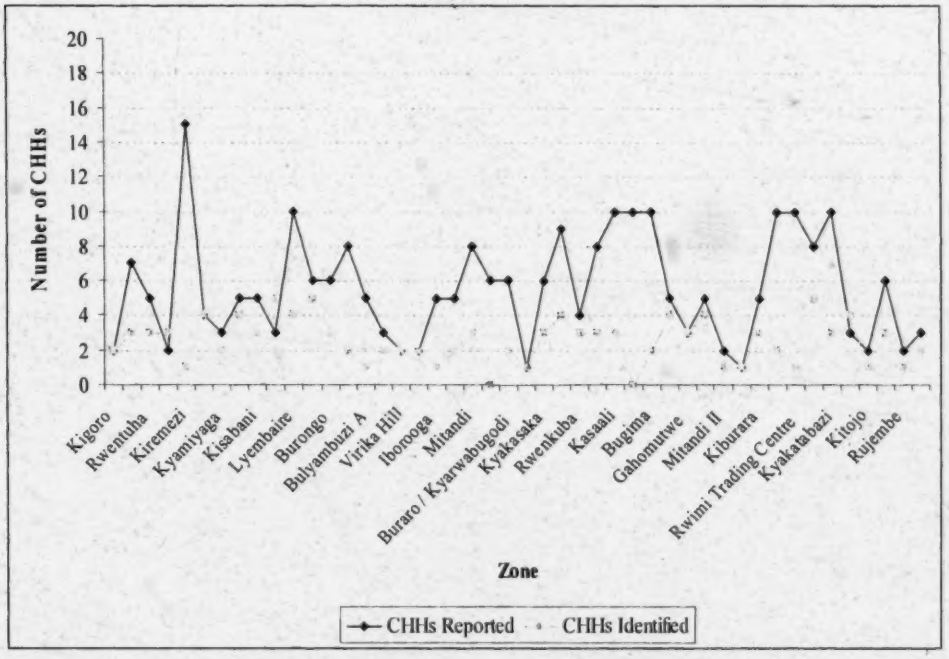


Figure 2.2.4 shows the discrepancy between the number of child-headed households reported and those identified in each of the 46 zones. Overall, of the 256 child-headed households initially reported by these 46 LC1s, only 116 households (or 45% of those reported) were identified. When applied to the overall initial estimate of 4727 child-headed households in Kabarole District, a 45 percent accuracy rate decreases the overall child-headed household estimate of the district to 2127 (95% confidence interval: 1613 to 2641) or two percent of all households.

2.3 Urban / rural differences

To assess any differences in the magnitude of child-headed households between urban and rural populations, and to identify whether any other distinguishable differences could be found in the LC1s' responses, opinions, and ideas, comparisons between urban and rural respondents were made. Throughout this

analysis, differences in the LC1s' responses are only shown when they were considered noteworthy.

Comparisons of the average number of orphaned children, the number of child-headed households, and the number of AIDS-related child-headed households between urban and rural zones show that there are, on average, more orphaned children, more child-headed households, and more AIDS-related child-headed households in rural areas than in urban areas, and that these differences are statistically significant. When calculated in proportion to the average population sizes of those zones, however, this difference is no longer apparent. On average, rural zone populations are notably larger (median: 522) than urban zone populations (median: 300), which is not surprising given that an estimated 89% of the population in Kabarole District lives in rural areas (Uganda Bureau of Statistics, 2006). Table 2.3.1 shows that these differences are not statistically significant when considered in proportion to the overall population sizes of the urban and rural zones.

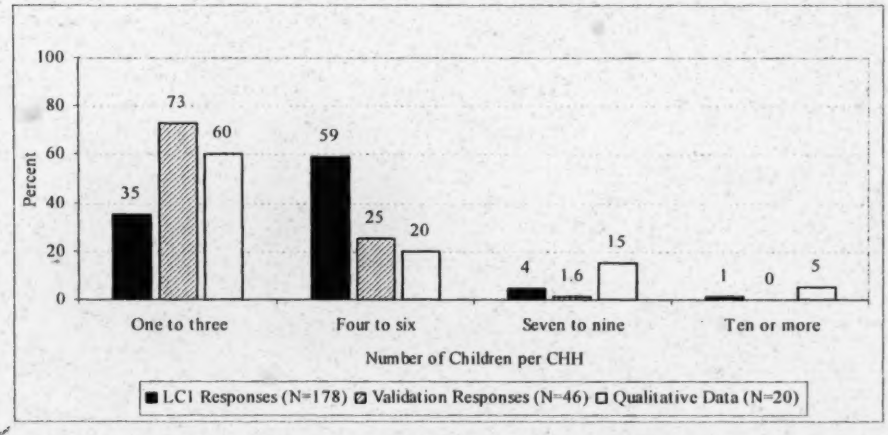
Table 2.3.1. Mann-Whitney U test for equality of ranks

	Location	N	Mean Rank	Mann-Whitney U	Asymp. Sig. (2-tailed)
Proportion of orphaned children per zone	Urban	20	86.93		
	Rural	155	88.14		
	Total	175		1529	0.919682
Proportion of CHHs per zone	Urban	20	73.55		
	Rural	157	90.97		
	Total	177		1261	0.152063
Proportion of AIDS-related CHHs per zone	Urban	20	76.65		
	Rural	156	90.02		
	Total	176		1323	0.268865

2.4 Size of child-headed households

LC1 respondents were asked to estimate the average size of the child-headed households in their zone. Those who reported no child-headed households in their own zones were asked to consider other zones and estimate accordingly.

Figure 2.4. Size of child-headed households



LC1s tended to report an average child-headed household size of four to six children (59%). When compared with the data collected from the child-headed households in which in-depth interviews took place, as well as the sizes of child-headed households identified during the validation process described above, their estimates are slightly exaggerated. Data from the 20 child-headed households interviewed for the qualitative component of the study show that the majority (60%) of households consist of one to three children, including the child head of household. Only 20 percent of these households were inhabited by four to six children, and 15 percent consisted of seven to nine children. Only one household (five percent) was the home to ten children. Results from the validation process show a similar trend. In the 46 zones where 116 child-headed households were identified, 68 percent of households consisted of one to three children. Thirty percent of the child-headed households visited had four to six children, and two percent consisted of seven to nine children. No homes had ten or more children. These data suggest that child-headed households generally tend to be small,

although large households consisting of anywhere from seven to ten children are not unheard of.

2.5 Trends

LC1s were asked to comment on the trends in the numbers of child-headed households they had seen in their zone over the last five or ten years. Those who had reported being the Chairperson of their zone for six or more years were asked to comment on the trend over the previous ten years, while those reporting five or fewer years were asked about the trend over the last five years. This was done to minimize the LC1s' speculation regarding the trends and to maximize the accuracy of the responses.

Sixty-nine percent of LC1s reported an increase in the numbers of child-headed households in their zones over the time for which they were questioned. Twenty percent noted a decrease, and the remaining 10 percent perceived that it had remained the same.

2.6 Urgent problems

As a proxy for the communities' awareness about the true nature of the conditions within which children in child-headed households live, and to assess the LC1s' cognizance of and sensitivity to the needs and challenges faced by children in such circumstances, respondents were asked to comment on the children's most urgent problems.

For this question, as for most other questions in this survey, respondents could give multiple responses. Most frequently, LC1s identified school fees (77%) as the children's most urgent need, followed closely by food (74%) and clothing (65%). Access to medical care (47%), the scarcity of bedding (44%), and the poor state of housing / shelter (43%) were also frequently mentioned. Approximately one-third of respondents noted a lack of school materials (37%), the presence of disease and/or infection (36%), and general poverty (34%) as urgent needs. Other

needs, all identified by a handful of respondents, were a lack of guidance and/or parental care (10%), loss of land (7%), absence of cooking facilities (6%), neglect of one's own health and/or having no time to care for oneself (2%), discrimination and stigma (2%), and the absence of education (1%). LC1s expressed concern about early marriages and early pregnancies for young girls, and child labour for young boys, explaining that children in these circumstances will do anything to get money if their situation is extremely dire. Related concerns were expressed about the lack of care and guidance available to the children, and the associated poor behaviour seen among these children. Respondents explained that these children lack counselling and guidance, often leading to moral decline. They observed that, in the absence of adequate care, the children are free to behave as they please, often becoming careless in how they live their lives.

Gaining access to education was brought up by several respondents as a considerable difficulty for these children. Concerns about the children's lack of proper nutrition, lack of government support, and financial constraints were expressed.

2.7 Support systems

LC1s identified existing support systems they deemed most effective for the support of child-headed households.

Figure 2.7. Effective support systems for child-headed households

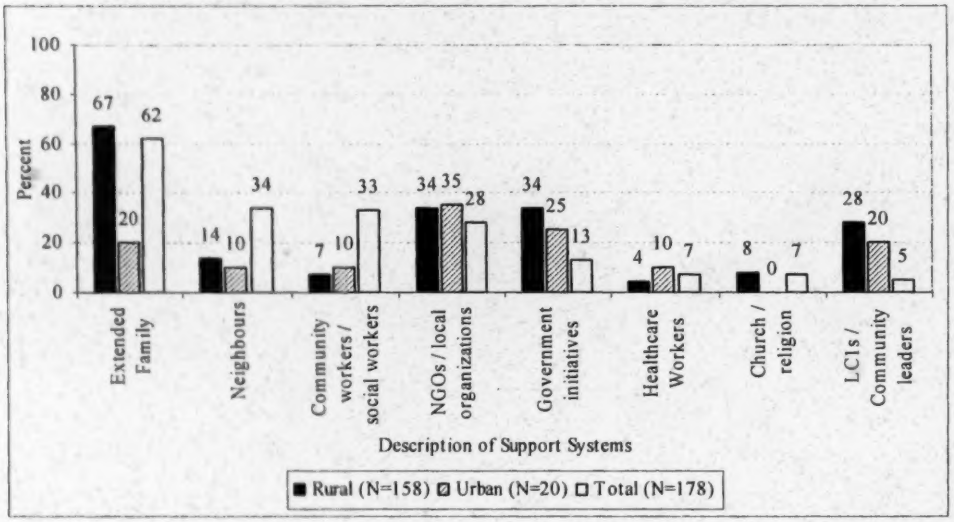


Figure 2.7 shows that respondents overwhelmingly identified the extended family as the most effective support system for children in child-headed households (62%). Non-governmental organizations (NGOs) and/or local Community-Based Organizations (CBOs) (34%), government initiatives (33%), and community leaders such as LC1s (28%), were also considered effective support systems. Other respondents mentioned neighbours (13%), community and/or social workers (7%), church and/or religion (7%), and healthcare workers (5%) as effective sources of support for these children.

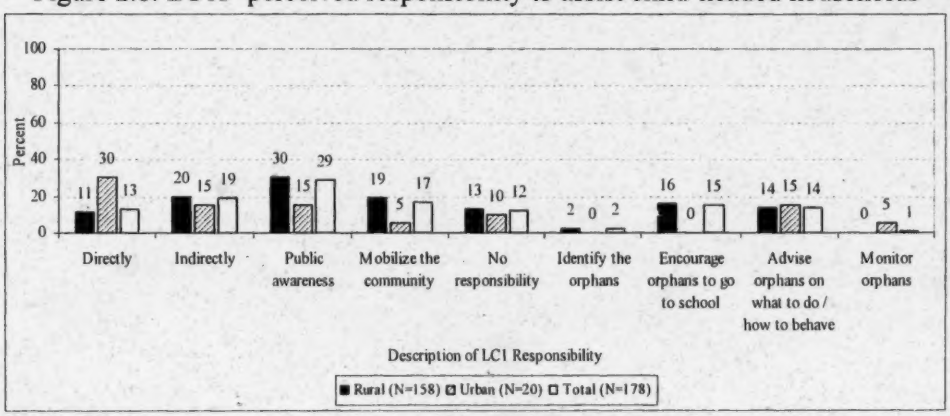
Many respondents expressed concerns about education, often suggesting that the government should offer financial assistance for orphaned children to attend higher institutions. They identified the necessity for material support and assistance with food for children in child-headed households. Children's access to safe drinking water, bedding, school materials, and other essential needs were also noted. Respondents proposed that government and NGOs should provide essential drugs and that housing and shelter for these children should be provided. Some respondents also suggested the development of income-generating projects, such as a piggery, to assist the children.

There was considerable variation between urban and rural responses to this question. Most noticeably, rural respondents identified the extended family as the most effective support system (67%), while only one-fifth of urban respondents identified this as an important form of support. This may be indicative of the contribution of urbanization to a diminishing recognition of the importance of the extended family in orphan care.

2.8 Responsibility of LC1s to assist children in child-headed households

As they are potential role models for their communities' responses to the orphan crisis in their villages, LC1s were asked to comment on what they perceived to be their own responsibility to assist children living in child-headed households.

Figure 2.8. LC1s' perceived responsibility to assist child-headed households



One respondent commented that it is the LC1s' responsibility to be supportive of the orphans in case there is any problem. As shown in Figure 2.8, almost one third of LC1s (29%) suggested that their primary role is to increase public awareness about the situation of child-headed households. Proportionately more rural respondents felt public awareness was an important part of their role (30%) than did their urban counterparts (15%). Other respondents mentioned that they feel it is their responsibility to indirectly support local organizations (19%) and mobilize the community to respond to the situation of child-headed households (17%).

Again, 19 percent of rural respondents felt that this was their role, while only five percent of urban respondents reported this. Respondents felt that community mobilization involves the task of encouraging the community to support orphans, to build shelter for them, and to link them to NGOs and other possible sources of support in their area. Some felt it is also their responsibility to lobby for financial assistance from sponsors or funding organizations.

Encouraging orphans to attend school was identified as the LC1s' roles only by rural respondents (16%), not urban respondents (0%). LC1s recognized that education is not accessible for all children living in child-headed households and, as such, noted that it is their role to encourage those who can to go to school, while guiding those who cannot afford to go to school on other ways or earning a living. Advising orphans on how to behave was also deemed of particular importance by the LC1s (14%). Counselling and guidance on education, observing patience, and being morally good were included in this. Advising orphans on how to cater for themselves and prohibiting them from antisocial behaviour, such as stealing, were also noted. Slightly more than one-tenth of respondents felt they should directly support orphaned children with school and/or medical fees. Urban respondents noted their role in assisting them directly (30%), while only a few rural respondents saw this as their role (13%). Others mentioned the need to provide assistance with housing and shelter for the children.

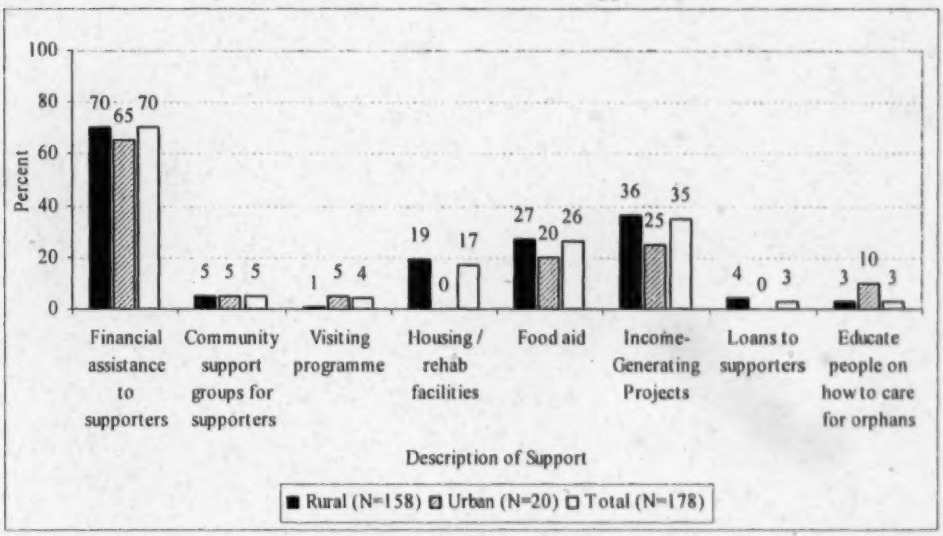
Some LC1s mentioned their responsibility in protecting these children from physical harm, land theft, and abuse, such as rape or assault. They mentioned their responsibility to protect the orphans' property left by their parents and to ensure the orphans' proper use of those properties. While they gave no specific evidence of familial abuse taking place, some LC1s felt they should advise caretakers not to abuse orphaned children and ensure that guardians or caretakers do not subject orphans to torture, suffering, or severe punishments. Others noted their role in making regular visits to children living in child-headed households to ensure their safety and well-being, providing counselling and consolation to them, and

encouraging them to persevere in any hardships they may face. Twelve percent of respondents felt they had no responsibility as LC1 Chairperson in addressing this problem, explaining that their role is limited because of the lack of support they receive from the government. While they feel concerned about orphaned children in their villages, they reported a lack of financial resources to be of assistance to them.

2.9 Government responsibility

The presence of informal support structures, such as members of the children's extended family, their community, neighbours, and other social structures have been identified as important avenues of assistance for orphaned children and those living in child-headed households. To focus on the strengthening of existing responses to and programmes for these children, LC1s were asked to propose avenues of government support to the informal support structures that already exist.

Figure 2.9. Government to assist support systems



The majority of respondents (70%) suggested the government assist informal support structures financially to enable them to assist orphans (Figure 2.9). Some

proposed that such financial assistance be given directly to the LC1s, while others proposed that the government should give the money to local societies that can help to educate orphans. A number of LC1 respondents (35%) identified income-generating projects (IGPs) as the most important way for the government to support informal support structures. This response was more common among rural respondents (36%) than urban respondents (25%), perhaps reflective of the limited capacity of rural populations to be gainfully employed in official jobs and their comparative advantage with the use of IGPs given their agricultural and animal husbandry skills. Respondents felt it was the government's responsibility to provide grants for the children or to start income-generating projects for them.

Less than one-third (26%) of respondents mentioned food aid as a method of government support for orphaned children. Fewer (17%) and notably only rural respondents (19%) identified housing and/or rehabilitation facilities (urban respondents: 0%). Negligible numbers of respondents identified community support groups (5%) or visiting programmes (4%) as useful ways for the government to be involved in supporting child-headed households, with proportionately more urban than rural respondents suggesting this as an appropriate means of support.

Few respondents (3%) suggested the government should educate community members about how best to care for orphaned children living in child-headed households, with proportionately more urban (10%) than rural (3%) respondents mentioning this. They proposed that the government teach communities to care for orphans, ensure that orphans are educated beyond the primary level, and arrange for workshops for LC1s and other local associations to sensitize the community on the situation of orphaned children. They suggested special committees be put in place to care for them. Respondent noted that, in order for these suggestions to be effective, the government should register all those who take care of orphans. Considerable caution about the monitoring of any financial arrangements was expressed by several LC1s.

2.10 Obstacles to assisting child-headed households

LC1 respondents were asked to identify the most pertinent obstacles challenging efforts to support children living in child-headed households.

Figure 2.10. LC1's perceived obstacles to assisting child-headed households

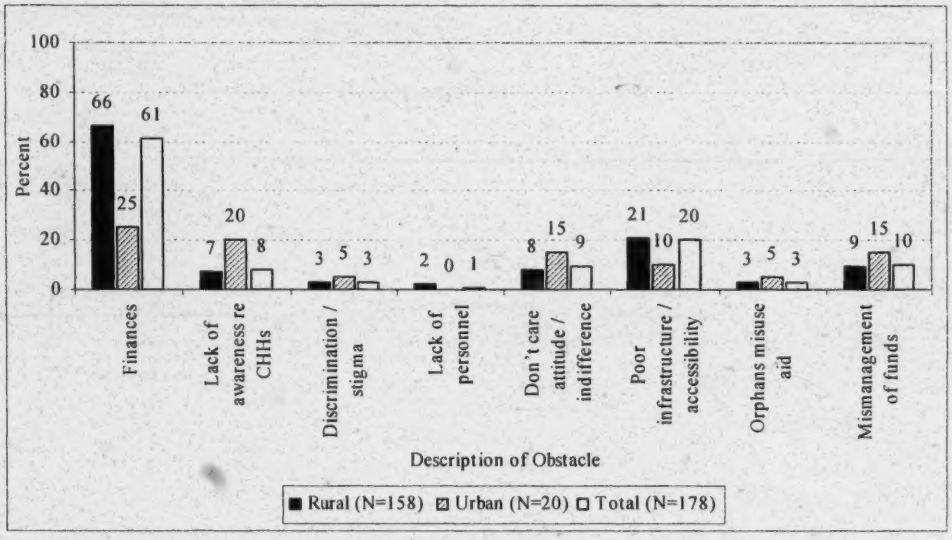


Figure 2.10 shows that limited financial resources were most frequently identified as the biggest obstacle (61%), particularly by rural LC1 respondents (66%), and less so by urban respondents (25%). LC1s noted the rampant poverty and low income rates in the area which limit the extent to which people can be of assistance through financial or material means to others. Poor infrastructure and accessibility was also mentioned by one-fifth of the LC1 respondents (20%) although this was more commonly cited by rural (21%) rather than urban (10%) respondents.

One-tenth (10%) of respondents mentioned the mismanagement of donor funds as an obstacle to assisting children living in child-headed households, proportionately more urban respondents (15%) than rural respondents (9%). Concerns about poor leadership, money embezzlement, bad governance, minimal or no follow-up, and the honesty of those handling funds intended for orphaned

children were also expressed. Dishonesty among 'concerned' people, the mismanagement of funds for personal use by the authorities, and the general lack of transparency among government officials were also mentioned. The government's indifference about the problem of orphaned children and child-headed households was identified as an obstacle preventing adequate assistance of orphaned children in child-headed households (9%), although more so among urban respondents (15%) than rural respondents (8%). The general lack of awareness and don't care attitude about orphaned children on behalf of the government, combined with poor planning and failure to respond to requests from local communities who send reports to government leaders on the situation of orphans were cited as evidence of its indifference to the situation. Other respondents felt that a lack of community awareness creates a barrier to assisting orphaned children (8%), this being overwhelmingly cited by urban respondents (20%), and much less frequently by rural respondents (7%). Discrimination and stigma (3%) as well as the orphans' misuse of aid provided to them (3%) were also mentioned. Several LC1s suggested that orphaned children's poor behaviour, moral decline, and their tendency to sell the items given to them discourage others from offering support. Lack of personnel was also noted as an obstacle in the way of assisting child-headed households (1%).

2.11 Opportunities for school attendance

The overwhelming majority (90%) of LC1s believed that children living in child-headed households have a worse chance of being able to attend school than do children who live in households with their parents or other caregivers. They explained that the children's extreme poverty and lack of basic needs lead to high absenteeism, poor performance, or even prevent them from being able to attend school. They noted that orphaned children drop out of school after primary education because they lack financial support and someone to take care of them. They added that orphaned children also often sleep hungry, which limits the extent to which they can succeed academically.

Only five percent of respondents felt that all children have the same opportunities, regardless of their home situation. They explained, however, that the orphans' equal opportunities for school attendance do not apply beyond primary school. In secondary school their chances are worse because of the school fees which are required. Others felt that, if orphaned children were provided with scholastic materials, they could have the same chance as other children of attending school. Three percent of respondents suggested that these children have a better chance of being able to attend school, and one percent of respondents did not respond to this question.

2.11.1 Enabling school attendance

LC1 respondents were asked to consider ways in which the evident inequity in the children's opportunities for school attendance could be rectified. Almost two-thirds (62%) of respondents suggested that government programmes should be responsible for paying the children's school fees. They suggested that LC1s should pressure the government to provide free education and that collaboration between government and NGOs, community organizations, and the orphans' extended families be encouraged. Less than one-third (27%) suggested that outside sponsors pay the children's fees, while others suggested that relatives or friends pay their fees (22%), or that community organizations (11%) or income-generating projects (11%) are used to pay for the children's fees. They proposed that village committees which deal specifically with the issues of orphaned children and child-headed households be put in place. Few respondents (3%) suggested boarding schools as a solution to this problem, while two percent noted that the children's burden at home must be lessened in order to facilitate their attendance at school.

2.12 Community response

LC1 respondents commented on the reaction of their communities to the situation of child-headed households in their zones.

Figure 2.12. Community response to child-headed households

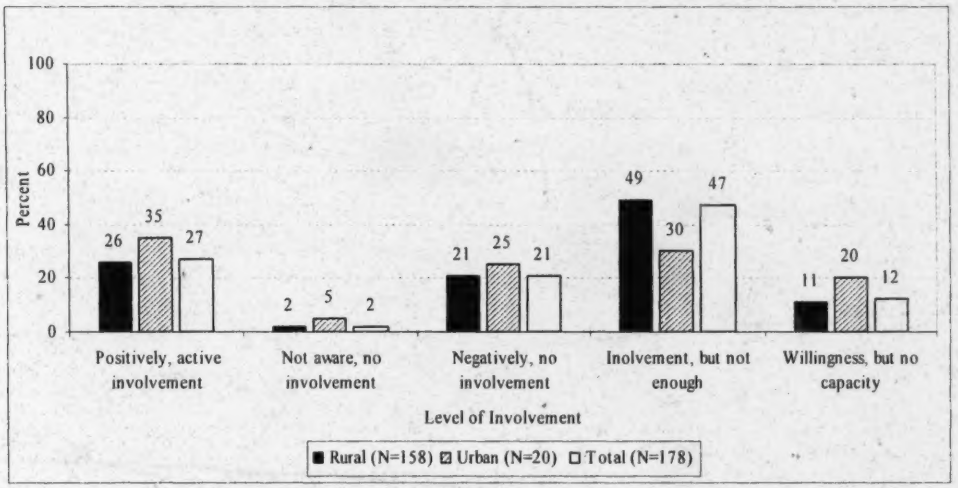


Figure 2.12 shows that almost half (47%) of the respondents reported that their community was involved in addressing the phenomenon of child-headed households, but not enough to have any notable impact on the children. This was the most common response among rural respondents (49%), though less common among urban respondents (30%). Urban respondents were more likely to report that their communities were responding positively to the situation of child-headed households, and that they were actively involved (35%), while only 26 percent of rural respondents cited this in their response. One-fifth (21%) of all respondents reported that the community's response was negative, as exemplified by their total lack of involvement. They mentioned that, with the exception of a handful of 'good samaritans', most people are passive about the problem of orphaned children and child-headed households and that people tend first to focus on their own families before thinking about how to assist others.

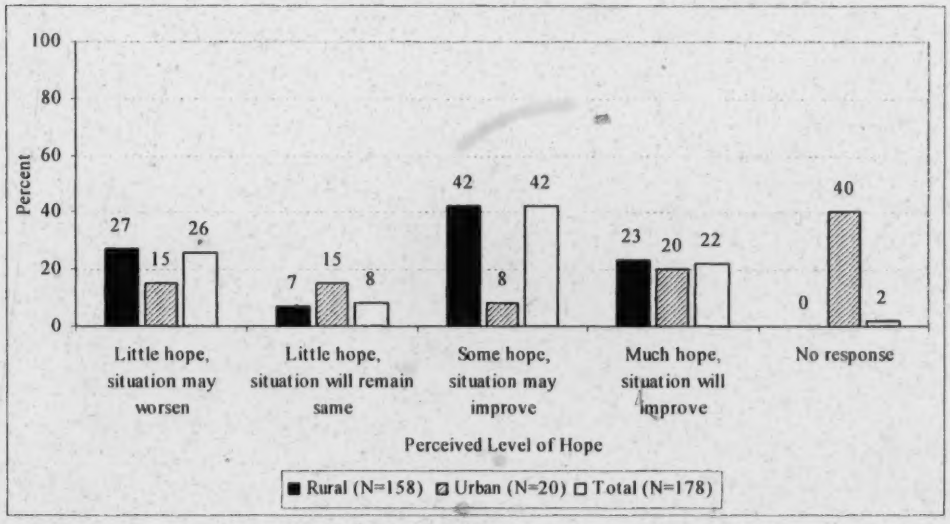
Approximately one-tenth (12%) of respondents felt that there was a general willingness among the community to be of assistance to children in child-headed households, yet noted that they lack the capacity to be of assistance to them. It is interesting to note that, despite a likely higher standard of living in urban areas, urban respondents were more likely to suggest that the willingness to respond was

impeded by limited financial capacity (20%), while only eleven percent of rural respondents felt that this was the case. The remaining two percent of respondents suggested that there was no involvement of their communities in addressing the problem of child-headed households because they lack awareness about the situation in their community. They explained that the public is not sensitized about the issue of child-headed households and therefore does nothing to assist them.

2.13 Hope for children in child-headed households

The LC1s' optimism or pessimism with regards to child-headed households in the region was assessed by asking, "What hope do you think there is that the situation will improve for children living in child-headed households in Kabarole District?"

Figure 2.13. LC1s' perceived level of hope for children in child-headed households



The LC1s' optimism with regard to the situation of orphaned children seemed to be determined by how well they perceived the government could respond, many of them suggesting that the children's situation will only improve if the government makes an effort to assist them. Figure 2.13 shows that 42 percent of respondents felt there is some hope that the situation for orphaned children may

improve, although rural respondents showed considerably more optimism with regards to the situation of child-headed households (42%), than did their urban counterparts (8%). Less than one-third (26%) of respondents predicted that there is little hope for child-headed households and believed their situation may worsen if nothing is done to avert the current situation. Rural respondents were more inclined than urban respondents to suggest that there is little hope and that they feared their situation would only worsen (27% and 15%, respectively). LC1s noted that the government has not made an effort to pay for orphaned children's school fees, and that their situation is worsening as no assistance has helped them financially with their educational pursuits.

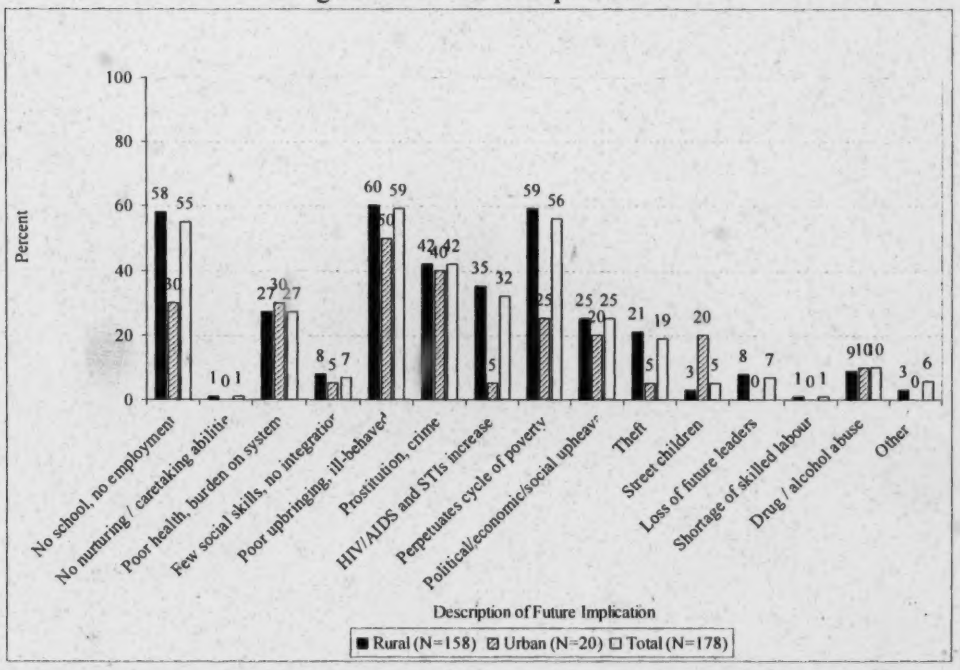
Almost an equal number (22%) of respondents felt that there was much hope, and that the situation for orphaned children in child-headed households will improve if there is timely assistance and the government mobilizes and instructs communities on how to care for and support orphaned children. They suggested that financial, moral, and material assistance is required from the government if the situation of orphaned children is to improve. Others expressed optimism about the situation of orphaned children, noting the many NGOs that are being developed to assist them. They expressed the need for other bodies to address the situation of orphaned children as well, predicting that if supportive organizations and individuals become seriously involved, the orphaned children's welfare could improve. They anticipated that, if the government responds to NGOs and CBOs by increasing their funding, the orphaned children's situation may also improve.

The remaining respondents (8%) felt that there is little hope and that the situation will likely remain the same. They pointed to the lack of local support particularly in secondary education, which significantly minimizes the children's hope for the future.

2.14 Future implications

LC1 respondents identified a variety of social, political, and economic outcomes they felt could affect the future of Uganda as a consequence of raising a generation of children without parents.

Figure 2.14. Future implications



As shown in Figure 2.14, the majority of respondents (59%) were concerned that orphaned children would have poor behaviour as adults as a result of their haphazard upbringing. Concern about perpetuating the cycle of poverty was expressed by many respondents (56%), although much more so by rural respondents (59%) than urban respondents (25%). The difficulties uneducated orphans may face in finding employment was also identified as a future implication of their present situation (55%), especially among rural respondents (58%) and less so by urban respondents (30%). Because they have not been raised well and lack even a basic education, the LC1s predicted, orphaned children will not be important to the nation when they are adults.

Other respondents feared an increase in crime and prostitution (42%). They anticipated that the country will be in chaos as orphans become thieves, get involved in illegal activities, and rebel against the government. The likely increase of HIV/AIDS and sexually-transmitted infections (STIs) (30%) was mostly a concern among rural respondents (35%), much less so by urban respondents (5%). The associated burden on the health system as this subset of the population will likely suffer from particularly poor health in adulthood was also predicted (27%). LC1s surmised that political, economic, and social upheaval as a fall-out from this situation will also ensue (25%). They were pessimistic about the future of the country, predicting that the country will not develop socially, politically, and economically, and that children who are raised as orphans will not be good citizens in the future.

Respondents, particularly those in rural areas (21%), expected that theft would be on the increase (only 5% of urban respondents mentioned this). The increase in the abuse of drugs and alcohol (10%) and issues concerning the lack of social skills and inability to integrate into society were also expressed (7%). The loss of potential future leaders (7%) was only mentioned by rural respondents (8%) and not by urban respondents (0%). LC1s felt that people who could potentially benefit the country are going to die prematurely, resulting in a lack of leaders and a population of uneducated people. An increase in the number of street children (5%) was of more concern to urban respondents (20%) than rural respondents (3%), presumably because they are more likely to see children living on the streets in an urban centre. In addition, unwanted pregnancies (3%), and early marriages (2%), as well as an absence of nurturing or caretaking abilities (1%), a shortage of skilled labour (less than 1%), and a decline in moral behaviour (less than 1%) were mentioned as future implications of raising a generation of orphaned children.

Chapter Three: Results – Qualitative

In this chapter, a variety of issues critical to the daily existence of children in child-headed households are explored. The children's most pressing concerns, which include most saliently their lack of basic household possessions, education, and nurturing, are considered first. Their overwhelming responsibilities as child heads of households are highlighted, and some of the characteristics that seem to assist them to cope with their daily struggles are outlined. The important issue of support for children living in child-headed households is explored, as are concerns about stigma and discrimination from schools, communities, and extended family members. First, however, the demographics of the households in which interviews took place, the level of official and unofficial support received by the respondents and their households, and the years of their parents' deaths are outlined.

3.1 Demographics and household composition

Table 3.1 shows the ages and gender of interview respondents and co-habiting children.

Table 3.1. Demographics of child-headed households interviewed

CHH	Respondent age & gender	Ages (years) of children	Siblings living outside the home	Years of parents' deaths	
				Mother	Father
1	17 ♀	15, 14, 12, 10, 5, 1 month	Sister ran away	2003	2003
2	16 ♂	14, 12	Step-brother lives with his mother	2004	2001
3	15 ♂	14	Four sisters in late mother's house, 26 year-old cousin lives with wife & family	2001	2000
4	14 ♀	10, 8	N/A	2000	2000
5	16 ♂	14, 12	N/A	2000	2005
6	17 ♀	15, 13, 12, 10, 6, 9 months	N/A	2005	2003
7	13 ♂	10, 8	Step-sister	2003	2003
8	18 ♂	15, 14	Two step-brothers	1997	1997
9	18 ♀	16, 14, 12, 9, 9, 2	Sister, married	2000	1997
10	16 ♂	13, 11	N/A	2005	1999

Table 3.1 (continued). Demographics of child-headed households interviewed

CHH	Respondent age & gender	Ages (years) of children	Siblings living outside the home	Years of parents' deaths	
				Mother	Father
11	16 ♂	13, 10	N/A	2000	2000
12	16 ♂	14	Sister lives in Kampala	1992	1994
13	17 ♂	16, 15	Three sisters	1994	
14	17 ♂	18, 16	N/A	2000	1999
15	13 ♀	14, 10, 8	Two step-brothers live with grandmother	2000	1998
16	17 ♂	16, 13	Two step-sisters live with their mothers	1990	1997
17	18 ♂	16, 13, 12, 6, 4	Four step-sisters live with their mothers	2003	2003
18	15 ♀	11, 10, 10, 9, 8, 7, 7, 5, 5	Brother lives in Kampala	2004	1999
19	15 ♀	12, 7, 6, 4, 3	N/A	2002	2002
20	15 ♂	14, 13, 10, 9, 8	N/A	2000	2000

The majority (16 of the 20) of respondents were siblings of all the other children in their households. Two respondents lived with their siblings and their own baby, one of which was one month old at the time of interviewing, and the other which was two years old. One respondent lived with her siblings as well as her nieces and nephews who had been left in her care after the deaths of her older brother and sister, increasing her burden as she inherits related children in addition to her own siblings. One respondent seemed to alternate between living alone and living with an orphaned friend who came to stay with him periodically.

As shown in Table 3.1, twelve respondents mentioned having a sibling that lives outside the home. These siblings were either 'full' siblings (from the same mother and same father) or 'step' siblings who share one common parent. One respondent reported that her sister had run away to escape the circumstances in which she and her siblings were living since their parents died. Another respondent's sibling was being sponsored to go to boarding school. Other siblings lived in Kampala, stayed with their parent who is still alive (the parent whom they do not share with the respondent), with a relative on the side of the family not related to the respondent, or with their spouse. The latter reason was particularly common among siblings in

their 20s. Respondents reported being visited by their out-of-home siblings, though there was no regularity to these visits, nor were they frequent. They seemed to have no means of contacting their siblings if they lived at any reasonable distance from them, and waited for their siblings to come to visit them.

3.2 Years since death of parent(s)

The time since the respondents and their siblings became total orphans ranged from three months to eleven years (Table 3.1). In about one-fourth of the cases, both parents died within the same year. In almost half the cases, the father died between one to six years earlier than the mother, and in only a few cases, the mother died prior to the father. The death of the children's parents did not necessarily lead to the immediate development of a child-headed household in all of the cases studied here, however. Some children lived with an extended family member upon the death of their parents and became a child-headed household only after that arrangement ended. Termination of such arrangements occurred because of the death or departure of the extended family member, or conflict between them and the children.

3.3 Support

Seven of the 20 respondents interviewed are officially supported, five of them by one NGO and two by a CBO that is part of a larger initiative to assist vulnerable populations within Kabarole District. Neither of these organizations focuses solely on child-headed households in its efforts, but rather has a mandate to assist particularly vulnerable children and families, a group which by definition includes children living in child-headed households. While other organizations of this nature exist in the district, only those households associated with the above two were part of this study. In addition to these seven households, respondents in two homes that had recently been registered by an NGO were interviewed. The names, ages, and particular circumstances of the home have been recorded, but support in the form of material or financial assistance has not yet been provided. The

remaining eleven homes in which interviews took place are unsupported, neither registered by an NGO nor being supported by any official sponsor.

Most respondents being officially supported by the NGO reported that the director of the NGO provides them with all their basic needs. They attributed their relatively decent living standard to her assistance, and were grateful for what she has done for them. The support from this particular NGO is well-organized, consistent, and predictable. The children know when they can go to collect the material assistance from her, and they are aware that if they are well-behaved and perform well at school, they will continue to be supported. Only one respondent reported supplementing what he and his siblings receive from the NGO by growing their own matooke (cooking bananas) which they can eat or sell for additional income. Most others felt that the food which is provided for them is sufficient.

For those who are not being officially sponsored, neighbours can be an important source of support, although this type of assistance can be sporadic and unreliable. Most children who reported being assisted by their neighbours explained that the neighbours provide assistance whenever they feel that they can. Some neighbours assist the children with food in return for the children's labour. One respondent reported assisting the neighbours in their millet harvest for which she is given some millet in return. Another respondent similarly explained that she and her siblings must work for her neighbour in order to receive her support.

> When she calls us to do her work, we do. We look after her children. (Female, 14 years)

This neighbour also lent the children clothes after all of their clothes were stolen from their home. Another respondent receives a loan from the local shop from where he buys scholastic materials in order for his siblings to be able to continue attending school.

> I go to the nearby shop and buy books or get them on debt such that they go back to school. (Male, 16 years)

He further explained that in times where he has very little money with which to buy food for himself and his siblings, he will go into debt to acquire some basic necessities.

> When I have not yet go my salary from work, and there are no bananas in the plantation, I'll just go and get things on credit and promise to pay the debt. (Male, 16 years)

These arrangements are likely an anomaly among child-headed households, however. This particular respondent is the only one of the 20 respondents in child-headed households that is officially employed, which likely increases others' propensity to trust him to repay the loan within a reasonable time. Other neighbours assist children in child-headed households by visiting them, checking in on them, and offering guidance and counselling. One family's neighbour assists the children with cooking. Because the respondent, the oldest child, and the other older siblings of this child-headed household attend school during the day, the two youngest children, who are four and three years old, remain at home alone. Clearly too young to cook for themselves at that age, their neighbour comes to cook for them every day at lunch.

For some children, their extended family members support them with whatever means they can. Similar to how the neighbours assist the children, extended family members at times bring food for the children, come to check on them, and bring soap when they can. A slight distinction between the assistance received from extended family members in comparison to that received from community members can be found in the type and degree of assistance given. Whereas neighbours are more likely to give assistance to the children in kind, extended family members seem to be more inclined to give financial assistance. In one instance, the children's uncle takes them to the hospital if they are sick. The brother of another family, who resided in Kampala, assists his siblings by paying

their monthly rent. In another instance, the children's step-brother gives them money twice a week for buying food.

3.3.1 Accessing support

Most respondents who are officially supported learned of the availability of support by word of mouth. This was either through a church, a relative, an LC1, or another member of the community. One respondent explained that his father had been part of the Church of Uganda where he found information about an NGO that assists orphaned children. Three respondents said that someone from their extended family connected them with an official sponsor that could assist them with schooling and other needs. One respondent explained that,

> Our aunt who stays in [another place] is the one who looked for [the sponsor] and she brought her here and she saw our situation and started giving us support. (Female, 18 years)

In one instance, an LC5 was responsible for connecting the children to a source of sponsorship. The LC1 told the children about an NGO in Fort Portal that assists orphaned children.

> The chairman assisted us after knowing that there was a mzungu [white person] who had come and was assisting orphans. So the chairman directed us and that is how we came to know [our sponsor]. My mother died when I was in P4 and I spent one year without going to school. When the Vice-Chairperson took me to his home and I started working, I spent one year working without being paid. Then when the Chairman saw me he told me about the mzungu in Nsorro who was assisting the orphans and then I left that job and that is when [our sponsor] started assisting us. (Female, 15 years)

Another respondent remarked somewhat cynically about the political motivations that inspired a government official to initially link him to his sponsor.

> When we were in P7, our teachers usually told us that in town there the organizations which help orphans. I started

> looking in the town, and there was a man who was standing at the post of a counsellor, LC5. Now when I went to him, he said that he, he knows someone who took care of orphans. He took me there, and [our sponsor] started helping us. (Male, 18 years)

3.3.2 Obtaining and maintaining support

For the most part, the children supported by an NGO go to the sponsor's office each month to collect their material assistance. From there they get food and other household necessities that are intended to last them for the month. Based on the information provided to us by the respondents, after some time, when the children have proven they are trustworthy and responsible, the director of the NGO gives the children money to buy their own food for the month. School fees are always paid directly to the school on an annual basis.

Children sponsored by an NGO are acutely aware of the necessity to be responsible members of the community and to perform well at school in order to maintain their support. They know that their support is not unconditional, and that they must use the assistance responsibly in order to continue to be assisted. The NGO responsible for supporting five of the seven supported households interviewed during this study requires that each child that is supported with school fees and other scholastic materials maintains a pre-determined ranking at school in order to continue to receive the support. One respondent explained how her support for school fees discontinued when she was not performing well at school.

> [Our sponsor] had put there a percentage that one was supposed to reach, and for me I had not reached that percentage. (Female, 18 years)

Similarly, another respondent explained that,

> [Our sponsor] says that when you don't perform well, she will not take us to S5 [the next level of school], but when you do well in that one, and you perform well, you will get to S5. (Male, 18 years)

Fortunately, however, this sponsor seems to be aware of the difficulties faced by some children in attaining a decent average at school, and does not completely cut off their opportunities for personal development should they fail to achieve this standard. This respondent continued,

> If I don't... perform well, [our sponsor] also told us that she can train us in other [inaudible], supporting us if we want to enter college. (Male, 18 years)

When asked if he meant "a trade as opposed to academics," he replied "Yes" (Male, 18 years). This sponsor also does not discontinue funding or sponsorship altogether based on a child's poor performance at school. If one child in a household performs poorly at school, only that child's school assistance is discontinued, yet the school support for the siblings as well as any other support (such as food or other basic needs) for the entire household also go unaffected.

3.3.3 Material support

Most frequently, official support prioritizes school fees and scholastic materials. Respondents explained that the director of the NGO that supports them looks after all of their school needs, including school fees for secondary school, uniforms, books, pens, and any other necessities required in order for the children to attend school regularly. She also gives monthly assistance with food or money and has provided mattresses and blankets when necessary. For those living in very poor housing conditions, she assisted them with constructing a more stable house.

> The house which we were in, the one which our parents left, was about even to fall down, and this one it was [our sponsor], she was the one who built it for us. She built a new one. (Male, 18 years)

Similarly, another respondent explained,

> [Our sponsor] has built us a new house. We had the old house which collapsed. And we were as if we were sleeping

> outside. And she has built us a new house, and she has done so many things for us. We had no beds, no mattresses, and she gave us all these things. (Female, 18 years)

This NGO also provides useful assistance to enable the children to seek treatment for health conditions whenever necessary. This is described in more detail in a later section.

3.3.4 Positive Impacts of Support

When compared to an unsupported home, the positive aspects of being supported by an NGO are obvious and readily identifiable upon entering the home. The physical state of the house in which the children are living can be seen as an indication of the children's supported status. Supported families' homes generally appear sturdier than those that are not being supported. The presence of material goods, such as mattresses, blankets, chairs or benches, bicycles, clothing, and other household and personal possessions are also an indication of the support they received. The availability of food and the frequency with which the children can eat a meal is notably higher among those being supported. While a number of the respondents who are not being supported reported eating only one or two times in a day, all of the respondents that are receiving official support from an NGO reported eating three meals a day when they are not attending school and, in only two of those instances, eating only lunch and supper if they are going to school in the morning and have no time to prepare food then. While no evidence of severe malnutrition or kwashiorkor was evident among any of the respondents, some of them and/or their siblings appeared to be stunted. This, however, is based on observations and was not measured as part of the study.

In addition to the material needs catered for by the sponsoring NGO, children being supported by the organization benefit in other ways. Most important is the opportunity to attend school, opening up possibilities for future self-sustainability that would otherwise be out of reach for them. This access to education is critical to the children's development, both mentally, emotionally, and socially. Many

children who do not have the opportunity to attend school reported feeling "bad" about seeing other children going to school.

Some supported children also reported going to their sponsor for psychological counselling and guidance.

> [Our sponsor] always gives us help to not enter peer groups which could lead us to problems. (Male, 18 years)

Overall, the impact of support on the lives of child-headed households is substantial. As one respondent described, her life and that of her siblings and baby have changed considerably since the NGO began helping them.

> Our life has changed. There is nothing much we require these days. In the past, we used to ask ourselves what to do, what to eat. But now we see ourselves being assisted very much, because she gives us food and gives us everything. And now we no longer worry about other people's things. We are just settled, and we just depend on what we are given. (Female, 18 years)

3.4 Household possessions

3.4.1 Bedding

Respondents and their siblings owned few household possessions. In particular, many of them lacked essentials such as mattresses and blankets. Bed frames were generally unheard of and only seen in two households, both of which were being officially supported by an NGO. The table below (3.4.1) shows the numbers of mattresses and blankets in each of the 20 households in which interviews took place. Distinctions between 'good' and 'bad' mattresses and blankets are based on the children's descriptions and/or the researcher's and interpreter's personal observations.

Table 3.4.1. Household possessions of 20 child-headed households interviewed

CHH	Level of Support	Number of Children in Household	'Good' Mattresses	'Bad' Mattresses	'Good' Blankets	'Bad' Blankets
1	Unsupported	6 plus baby	0	0	0	0
2	Unsupported	3	0	0	0	1
3	Unsupported	2	0	0	0	1
4	Unsupported	3	0	0	0	0
5	Unsupported	3	0	3	2	0
6	Unsupported	7	1	0	2	0
7	Unsupported	3	2	0	1	1
8	Supported	3	3	0	3	0
9	Supported	6 plus baby	6	0	6	0
10	Unsupported	3	0	2	1	1
11	Unsupported	3	0	0	2	0
12	Supported	2	2	0	2	0
13	Supported	3	3	0	1	2
14	Unsupported	3	0	2	2	0
15	Supported	4	3	1	4	0
16	Registered for support	3	1	0	0	2
17	Registered for support	6	3	0	2	0
18	Unsupported	10	2	3	4	1
19	Supported	6	3	0	1	1
20	Supported	6	3	0	3	0

As the above table shows, of the 20 households in the study, only six households had enough mattresses and five households had enough blankets for every child in the home. These include mattresses and blankets of deplorable condition which do not offer much support or warmth. Three households had enough mattresses for two-thirds of the children, five households had enough mattresses for half of the children, one had enough for one-third of the children, and five households had no mattresses whatsoever. The situation regarding blankets was similarly dire. Seven households had enough blankets for two-thirds of the children, three households had enough for half the children, three had enough for one-third of the children, and two households did not own any blankets at all. In most instances, the blankets that the children did own were old and torn, and the children complained of feeling cold at night.

Children without mattresses and/or blankets were creative in their creation of alternatives. Several children described using dried banana leaves, dried grass, or cotton placed into sacs in lieu of a mattress. Those without blankets reported

using bed sheets (sometimes one bed sheet shared between several children) or, in one instance, a jacket, to cover themselves at night. In some households, mattresses and blankets were shared among the girls in the home, while the boys slept alone. In the three cases where an infant or toddler was part of the family, the respondent (in all instances female) shared a sleeping space with the young child.

3.4.2 Animals

Few respondents owned animals. Some families owned chicken, fewer owned a goat, one respondent owned a rabbit and one respondent owned a pig. No respondents owned a cow, which is of little surprise as cows are seen as indicative of a relative level of wealth in this society. The desire to own animals was strong among most respondents, particularly those not attending school who see few options for sources of income now and in the future.

3.4.3 Clothing

All of the respondents and their siblings lacked sufficient clothing, particularly warm clothing to protect them from the sometimes cold temperatures of the region. Although Uganda lies on the equator, the western region experiences the highest amount of rainfall in the country annually and temperatures can get quite low in the colder months. Given the poor condition of most of the children's homes, they get cold and require warm clothes, at minimum something with long sleeves, to keep them reasonably warm. One respondent owned a jacket which was left to him by his father, and another purchased a jacket with the income he had received from transporting others on a motorcycle. Some respondents and their siblings had only a sweater for attending church, others had borrowed some warm clothes from a friend or neighbour, and some had a sweater they had already owned while their parents were alive and continued to wear it years later. When asked what the children do to stay warm if it gets very cold, respondents often explained that they "just stay like that" (Female, 17 years).

3.4.4 Land

Only one of the 20 families included in the study was renting the home and land on which they lived. Together, the two rooms shared by the ten children cost UGX 10 000 (CAD$6.33) per month. This is paid for by an older brother that stays in Kampala with the help of a friend to the late mother, who also assists them in other ways. A significant disadvantage of renting a home is that, as tenants, the children are not entitled to use or sell any of the crops that are grown on the land. One family, although not renting, does not officially hold the title to the land on which they reside, as there is an ongoing dispute with the father's sister over its ownership. The 18 remaining respondents interviewed in this study reported owning the land on which they live. For some, this was officially recorded in a will that entitled the children to own the land, while for others they simply assumed ownership of the land upon their parents' deaths.

Although there is considerable seasonal variability in the quantity and quality of the children's harvest from their land, the ownership of land and its use for subsistence farming assures at least some source of food for the children. Land ownership also provides security and stability in that it can be sold should the need arise. Most of the respondents reported using the land as a source of food and, in some instances, income. In times where there is a surplus of crops, children reported selling some of their harvest to other people in their area or at the market. They tended to feel a strong sense of responsibility for looking after and maintaining the land they inherited, explaining that they are automatically identified as the heir of the land upon their parents' deaths. One respondent explained that leaving the land to go elsewhere is not an option for him as an heir because of cultural reasons.

> You know, I was the one who was left as an heir. It is not allowed in our clan, if you are left as an heir, to leave your land and go somewhere else. (Male, 18 years)

3.5 Education

Limited access to education was of particular concern for most of the respondents. Overall, nine of the 20 respondents reported that all of the children in their households were attending school. In four households, two-thirds were attending, in two households, half the children were attending, in three households, one-third were attending, and in two households, none of the children were attending school. With the exceptions of three babies and two children under the age of four, all of the other 83 children that were part of the families interviewed in this study were of school-going age. The proportions given here used a denominator of only those children of school-going age.

In homes where only some of the children were attending school, it was predominantly the younger ones (those in primary school) who were attending, although not necessarily on a regular basis as they often lacked uniforms or other required scholastic supplies. The respondent and siblings of secondary school age had often stopped going to school. Some children lacked uniforms altogether, while others had an old uniform which they constantly wash and try to keep from becoming too damaged to avoid being sent home from school. Shoes are also required at most schools, and many children do not own any shoes. Respondents reported being required to pay money for Parent Teachers' Associations (PTAs), the construction of latrines or school buildings, rent for their teachers' residences, and chalk for the classroom. Many children who come to school without scholastic materials such as books, pens, and pencils, are sent home. One respondent explained,

> These days I'm not going to school because I don't have uniform and books. I went to school and they just sent me back home. (Male, 15 years)

Those who are attending school, however, find various ways to pay for the school fees and other scholastic requirements. For some, an official sponsor pays for the school fees and provides the children with all the required scholastic materials.

Others receive assistance from neighbours, friends, or relatives, who assist the children with their school fees when they feel they can. In many cases, particularly if children are asked to pay additional fees for the school that are separate from school fees, such as for the construction of latrines or classrooms, the purchase of chalk, or the rent for their teachers' accommodations, the children sell matooke to come up with the required fee.

3.5.1 Plans for secondary school payment

Children are well aware of the school fees required for secondary school. At the time of interviewing, some respondents and/or their sibling(s) were nearing the level of primary education where, upon passing exit exams from primary school, they are eligible for entering secondary school. Respondents were asked about their ideas for paying secondary school fees. One respondent had no ideas about how he could pay secondary school fees, although he did mention his intention to continue with his education to attain his goal of becoming a doctor or a pilot. Another respondent mentioned that, in addition to the money his brother earns by transporting people in the neighbourhood on a bicycle, he will sell matooke and hopefully raise enough money to pay for the school fees. Another respondent had planned to ask her brother for financial assistance when she attends secondary school. Finally, another respondent planned to arrange for his goat to become pregnant and provide offspring which he can sell when it is time for his younger brother to enter secondary school.

3.6 Needs

The most pressing needs expressed by respondents are those related to education. School fees, books, uniforms, shoes, and other such school requirements are grossly lacking. Recognizing the value in education, and the opportunities that are available only for those who have completed secondary school or beyond, the respondents expressed a very strong desire to attain the education to get themselves and their siblings out of poverty. Respondents also conveyed concern about the shortage of food and the inconsistency with which they have access to

it. Their need for warm clothing to protect them during the colder times of the year was mentioned, as was their need for bedding, such as a simple mattress and wool blanket as their current sleeping arrangements are inadequate and compromise the children's ability to rest properly at night. Soap, firewood, a bicycle, chairs, shoes, a radio, and advice about how best to tend to their plantations were also noted by respondents as their most urgent needs. Understanding the income-generating potential of owning animals, such as goats, chicken or rabbits, some respondents identified these as an additional request.

3.6.1 Adequacy of government response

A part of an attempt to assess how government involvement in the orphan crisis trickles down to those in most desperate need, such as those living in child-headed households, respondents were asked about the adequacy of the government's response to their situation. Their opinions about whether or not the government had done enough to assist them in their situations were almost evenly split across the 20 respondents, nine of the respondents stating that it was sufficient, and eleven of the respondents feeling that the response was insufficient.

The nine respondents who expressed satisfaction with the government's response to orphaned children identified several factors that influenced their opinion. Three respondents mentioned the existence of Universal Primary Education (UPE) which they felt has benefited disadvantaged children. Two others identified the protection offered from LC1 Chairpersons as a source of government assistance. One respondent had previously received material support from the government and considered that as evidence of its concern. Another respondent regarded the reduction of school fees and the government's promise of Universal Secondary Education (USE) in the future as exemplary of its support for orphaned children. A sponsored respondent was pleased with the government's stance towards NGOs, noting that it permits NGOs such as the one sponsoring him to be run by foreigners within Uganda.

Contrary to these praises almost half of the respondents felt the government's response to their situation has been inadequate. The reason for this was that the children had not yet received any support from the government. This absence of direct assistance from the government indicated to the children that the government was not responding adequately. When asked what they would request from the government should they have the opportunity, many respondents felt they would ask the government for assistance with school fees. Assistance with food was also urgently requested, as were mattresses, blankets, and clothing. Requests for assistance with housing, school uniforms, protection, and counselling followed. Other avenues through which the respondents felt the government could be of assistance to them is through the provision of books, goats, home necessities, seeds, bicycles, and access to adequate healthcare, as well as assistance with income-generating projects such as raising rabbits that can be sold or constructing a home that can be rented out.

3.6.2 Community assistance requested

In addition to the request for government involvement, respondents were asked to comment on ways their community could assist them. Several respondents reported that they expect nothing from their community. One respondent, who is employed as a security guard in Fort Portal, noted the poverty that surrounds him and explained that he could not ask them to assist him.

> As you go on, you find that those people, or the community around me, they don't have even the job I'm working. (Male, 16 years)

Another respondent who also does not ask her community for assistance explained simply that they are doing their best to assist her and her siblings, and that she would not ask for any more assistance from them.

Others, however, suggested that community members could give them money or provide food in exchange for work in their plantations or homes. Many

respondents expressed a request for community assistance with school fees and school materials. Requests for medications, food, and other basic necessities such as soap and clothes were made several times. One respondent requested that the community assist him in constructing a house. Another requested assistance in the garden. One suggested that his neighbours can help by giving him advice on how best to dig his plantation. A few respondents suggested that, while their community members are also living in poverty and cannot be of assistance to them through material support, they could assist them through counselling and guidance. Similarly, another sponsored respondent replied,

> Those people in the village are assisting in advising us... they don't have anything they can give you. (Female, 18 years)

Respondents were also asked about what any remaining extended family members living within reasonable distance could do to assist them. For the most part, their responses paralleled those of the question about community support, identifying books, food, and assistance with making their home sturdier as primary areas of requested assistance.

3.7 Head of household responsibilities

3.7.1 Challenges

The death of a parent leaves a considerable burden on the children left behind. Someone must take on the role of caregiver, and this responsibility almost always falls on the shoulders of the oldest child in the home. One respondent, whose parents died three years earlier when the respondent was 12 years old, described,

> My parents, when they were still alive, they used to tell me, 'when we die, look after these young ones, because you are the older'. When our parents died, they told ... me that I'm the oldest sister, to stay with them, not to leave them alone, so I have to stay with them. (Female, 15 years)

The responsibilities resting with the head of the household are many. Most urgently, the head of the household must cater for their own and their siblings' material needs. The respondents identified these responsibilities as some of the most difficult aspects of heading the household. Respondents repeatedly mentioned the considerable difficulty of providing adequate food, clothing, shoes, money, bedding, school fees, school uniforms and scholastic materials for their siblings and themselves. Illness among the siblings and the challenges in finding treatment for their illnesses were also causes of considerable stress and worry. Altogether, the situation is difficult and complicated, "being the head of the family when you can't manage it" (Female, 17 years). In addition to concerns about providing material needs, social and personal aspects of guidance and behaviour also become part of the head of household's responsibility. Respondents reported feeling responsible for guiding their siblings, teaching them how to behave, and telling them how to talk to others.

3.7.2 Chores

Children in child-headed households are faced with the responsibility of taking care of the entire household. Chores the children in child-headed households are often required to attend to include fetching water, collecting firewood, cooking meals, washing clothes, tending to the garden, and maintaining an orderly house.

Water and firewood

Almost all of the households in which interviews took place have access to some sort of gravity water scheme or a well nearby. Only one respondent reported regularly going to the river to fetch water, while a few others mentioned doing so in particularly dry seasons when the water in the well was insufficient. Children reported collecting water anywhere from three times a week to three times a day, depending in part on the number of children in the household available to assist in fetching water and the distance to the source of water. One respondent had a water source on his land, and others walked anywhere from five to twenty minutes to fetch water. They reported that, in drier seasons, it could take up to one hour to reach a water source on foot. Everyone in the house, including the young

children but excluding toddlers and infants, is responsible for collecting water. Young siblings assist by carrying a very small jerry can of water. One respondent, the oldest of seven children, explained,

> We old people, we go with these 10-litre jerry cans, and those [young] ones go with these three-litre jerry cans. (Female, 17 years)

Respondents explained that either all of the children go together to collect water, or they take turns fetching water while others are at school or stay home to cook, clean, or take care of the youngest siblings.

The chore of collecting firewood, which is used for cooking, was also shared among all the children. Some reported taking turns in collecting it, while others went together at the same time. Firewood was usually collected from a forest nearby, though some of the households that are sponsored by an NGO were provided with charcoal. Children collect firewood once a week or once a day, or anything in between, at a walking distance of five minutes to one hour. One respondent mentioned that, if nothing is available from the forest, he buys firewood from the trading centre at a cost of about UGX 1000 (CAD$.66) per week, using the money he earns selling matooke from their land. Another respondent, who is sponsored by an NGO but does not receive sufficient charcoal for the two months for which it is intended, reported buying firewood for UGX 3000 (CAD$2) to last the family for one month. She explained that she buys the firewood because she cannot simply take firewood from anyone's land.

> We wait for those firewood vendors, and we buy it from them. Some people don't allow you to go to their forest to collect firewood. If they find you in their forest, they will arrest you, and you'll be forced to pay for that firewood. (Female, 18 years)

Another respondent explained that her parents had planted a forest for them.

> Down there we have a forest. We have somewhere where our parents planted trees for firewood. (Female, 15 years)

Other household chores

Children living in child-headed households are also responsible for cooking, cleaning, washing, and other household chores. Those who are old enough, regardless of their gender, tend to be responsible for washing their own clothes, while an older sibling may wash the clothes for the younger siblings. In some instances, the oldest child delegates responsibilities to the others to ensure that all the chores are taken care of.

> When I wake up in the morning, I tell them to do different home chores. For example, I tell one to sweep the courtyard and I tell the other one to wash the dishes, and for me I go to the garden. Then, after coming from there, as they have collected water, I just cook for them, and they eat. (Female, 18 years)

Most of the respondents explained that they learned how to carry out their daily chores as a natural factor of growing up in a household, and that they had observed their mother cooking, cleaning, washing, and tidying. Others were too young when their parents died, and were required to teach themselves how to carry out these chores.

> With cooking I taught myself, but my sister taught me peeling [vegetables]. (Male, 15 years)

This lack of important knowledge transfer from parent to child is noteworthy and is explored in the discussion section of this report.

3.7.3 Caring for ill parent

Most respondents reported having been responsible, at least in part, for caring for their ill parent during the time in which s/he was dying. If available, a relative or neighbour often came to assist the children in this task. In instances where a relative or a neighbour was not available to assist, the oldest child took sole

responsibility of caring for the ill parent. One respondent, who was responsible for caring for his dying aunt who had come to live with him and his siblings after the death of their mother, reported that he knew how to care for his aunt when he was only 13 or 14 years old as she would instruct him to get tablets or other necessities for her. Respondents expressed having feelings of sadness during this time, some of them having been very young at the time of the death of their parent(s). One respondent was only five years old when his father died, his mother having died when he was three years old. His older sister, who was then twelve, took care of the respondent and his siblings during this time yet has also since died and left the young children to look after themselves.

3.7.4 Own children

Two female respondents have a baby of their own whom they must look after. These young women share a similar experience of having become pregnant at the age of 16 while still attending secondary school. In both instances, the father of the baby was the girl's short-term partner and left as soon as he heard of her pregnancy. Neither of these two young mothers has received any support from the father of the child, nor are the fathers' current whereabouts known. These respondents and local community members with whom informal discussions were held suggest that it is customary in this culture for a man to be responsible for providing a woman with her personal and household needs upon entering into a relationship. As one respondent explained, her boyfriend was supporting her until she became pregnant, at which time he left and stopped supporting her.

> I was in a secondary school … and I had a sponsor who was paying for me school fees, but I ended up getting a boyfriend who gave me other needs and I became pregnant. (Female, 17 years)

Later in the interview, when discussing how she obtains material needs such as sugar, salt, or maize, the issue of the respondent's boyfriend arose again.

> He stopped giving me money. He even ran away. (Female, 17 years)

3.8 Characteristics of head of household

In the face of substantial adversity, children living in child-headed households show considerable resilience as they cope with their circumstances. When asked about how they manage to cope, most respondents replied that they simply have no choice but to learn to cope.

> I'm seeing there is nobody else who can assist me, so it's me to take up the responsibility. (Male, 15 years)

Respondents recognized the difficult situation within which they find themselves, and felt they have no choice but to take it as it is. One respondent, who is responsible for six siblings ranging from nine months to 15 years of age, responded,

> I think I just take it easy as things happen. (Female, 17 years)

Respondents seemed to have difficulty identifying specific personal traits, qualities, or characteristics that assist them in coping with their daily challenges, yet thorough analysis of the 20 interviews provides some insight into what could potentially be personal qualities influential in differentiating those who are able to cope from those who suffer tremendously with their circumstances. Children's behaviour and age, the age gap between the children in the home, the passing of time since the parents' deaths, their physical demeanour, the level of support from neighbours, relatives, and friends, and the children's optimism with regard to their futures seem to be influential in this regard.

3.8.1 Behaviour

Respondents alluded to the importance of being well-behaved in order to garner support and sympathy from neighbours, friends, and relatives. According to the

children, good behaviour is integral to coping well and being accepted by the community. Attending church regularly, staying at home instead of moving about, and working hard were all mentioned as indications of 'good behaviour' that assist the children in coping with their difficult circumstances.

3.8.2 Age

Although very young child heads of households were not included in this study for the reasons outlined in the study methodology, the 13 to 18 year-old respondents in this study nevertheless expressed concern about their age in relation to the responsibilities they carry. Many of them felt too young to be taking on the responsibilities of parenting their younger siblings.

> My age is not enough for me to look after the family, and to give everyone anything he or she asks from me. (Female, 17 years)

Another respondent, who generally stays alone but at times lives with a 14 year-old orphaned friend in his home, expressed his concerns about being alone.

> I feel bad. I couldn't believe at this age of mine to be staying alone. (Male, 15 years)

Respondents' ability to cope seemed in part to be influenced by their ages, with younger and physically smaller respondents finding their situation more challenging than older respondents. While the respondent's gender may confound this factor, the influence of age in and of itself seems nevertheless to be at least partially influential. Using what are perhaps the extremes of these characteristics in comparing the circumstances of a 17-year old male respondent who lives with his 16 and 18 year-old brothers to that of a 14 year-old female respondent who lives with her ten and eight year-old sisters, this distinction between their capacity to cope with their situations in child-headed households is clear. The respondents' capacity to find employment, even if informal employment such as assisting neighbours with chores and other tasks, the amount of income they are able to

generate in a given week or month, the foods they eat, and their emotional wellbeing differ quite noticeably between the two.

The older of these two respondents listed a number of ways through which he and his brothers earn income, including transporting others on a bicycle, assisting neighbours in constructing houses and pit latrines, selling matooke, beans, potatoes, eggs, and piglets. This enables them to pay school fees for one of them and provides sufficient income to supply three meals a day. Moreover, despite the interviewer's considerable prompting about the respondent's fears, the respondent maintained that there is nothing he fears.

> We would fear thieves, but they don't come here... The thieves are there but... they haven't taken anything from us. (Male, 17 years)

The respondent's optimism about the future was also evident.

> I think that when my brother goes to secondary school, then I will also go back to school... [My brothers and I] all agreed that when the situation allows after school, we shall be doing something from where to get school fees. (Male, 17 years)

Overall, this respondent displayed strength and optimism, and identified a variety of means through which he and his siblings are able to sustain themselves. This young family's ability to look after itself and manage despite living in a child-headed household is readily apparent.

In sharp contrast, the younger respondent's capacity to make a living that can sustain herself and her sisters was extremely limited. Although she reported assisting neighbours in weeding and digging about three or four times each week, the money generated each day by the three of them is very little (UGX 1500, CAD$1 a day). In exchange for cassava and beans from her neighbour, the respondent also looks after the neighbour's five young children. This respondent reported that, with this limited income, she and her sisters eat only once a day.

She expressed considerable fear and anxiety about the wellbeing of herself and her sisters, worrying that people will come to hurt them. Having previously experienced intruders in her house at night, these are legitimate and urgent fears. This respondent showed little optimism about her future, expecting that she will continue to suffer as she does now, lacking many things such as soap, school uniform, and food. The limited capacity of the girls in this household to see themselves through the coming years safely and with reasonable health is of notable concern.

Although this comparison has used what are likely the most illustrative cases of the effects of age on children's capacity to cope in child-headed households, similar, albeit perhaps less extreme differences could be found in the comparison of other respondents' situations.

3.8.3 Age gap between siblings

The difference in age between the respondent and his or her siblings seemed to affect the children's relationship with one another and the head of the household's capacity to cope with his or her extenuating circumstances. The age difference seemed to be of particular importance in determining the level of respect for the oldest sibling. With one exception, where the 18 year-old young man was considered to be a father figure for his 17 and 16 year-old brothers, siblings who were separated by only a small age gap often shared the responsibilities of caring for the youngest siblings while sustaining the family financially and materially. While such a family composition of several siblings in close succession to one another can be helpful to the oldest child as it tends to lessen the burden s/he carries in looking after the siblings and the household, this type of family structure may also negatively affect the oldest child's capacity to effectively run the household. As one respondent explained, the small age gap between himself and his siblings, and the fact that his siblings are also entering their teenaged years, makes it difficult for him to continue in his role as the 'father'.

> You know when they were still young, they could respect me, but now they have started growing up. Anything I'm telling them, they sometimes don't... take it from me, and when we tell them to work, sometimes they refuse. (Male, 18 years)

Similarly, another respondent described her difficulties with her younger siblings.

> Now there are other children, you send her to do something, she refuses, or even abuses you. Such a child I just ignore. (Female, 17 years)

Part of the frustration about the siblings' disrespect for the respondent as a 'parent' likely comes from the conflicting role of taking significant responsibility for the well-being of the family yet not being recognized or appreciated for this effort.

For the most part, however, respondents reported feeling respected by their younger siblings, noting that they are listened to and generally regarded as the parent of the family. Child heads of households also showed a considerable sense of responsibility in caring for their siblings and ensuring their school attendance, often sacrificing their own education to provide for the others. One young man who is employed as a security officer in Fort Portal described his sacrifice for his siblings.

> I left school to work in order to get money to buy food and scholastic materials for my brothers. (Male, 16 years)

Because of his concern for his siblings during the night when he is away at work, this respondent spoke of his intention to leave his job so that he can be at home to care for his siblings.

3.8.4 Support

Although the support children in child-headed households receive from neighbours, extended family, and friends is clearly not a quality of the child's

character, it is a contributing factor to the children's capacity to cope with their situations. Observations suggest that a reasonable level of support received by the children positively influences their capacity to deal with their situation. In addition to the obvious advantages of obtaining material support such as food, soap, or school needs, neighbours' respectful and sympathising attitudes towards the children can have positive effects. The supportive person's encouragement of the children's perseverance and their expressed concern for their wellbeing provides much-needed guidance for the children, indicates to them that they are cared for, and noticeably assists them in their coping strategies.

3.8.5 Role of Local Council 1 Chairpersons

Some respondents spoke of their relationship with the LC1 in their village. In only one instance, the LC1 was specifically reported as not being helpful as he did not respond adequately to the children's complaint about their neighbours' disruption of their plot of land. Most respondents, however, talked about the LC1's role in protecting them. In one instance, the LC1 arrested the children's neighbour who had come to pour water on their mattresses as a reprisal for one of the children's act of taking a sugar cane from her plot. Others spoke of feeling protected by the LC1, knowing that if they tell him of their plight of having things stolen from them, they will be protected. One respondent reported an incident of people coming to rape her and her siblings to the LC1, who has since come to check on them three times a week, especially at night, in order to ensure that they are not being disturbed any longer. Another respondent explained that when he tells the LC1 of his concerns about his grandmother who is trying to steal the land from him, the LC1 offers protection.

> They hold meetings and [the family land problems] end.
> (Male, 16 years)

Another respondent who is afraid of thieves in her area feels protected by the LC1s who live nearby. Stating that the LC1s in her village are aware of her problems of potential theft, she described,

> There are times when [the LC1s] keep around to protect us. The [LC1s] here have guns. Sometimes they guard at night and there is a time when they caught thieves. (Female, 18 years)

Other respondents reported feeling supported by their LC1. One respondent described the LC1's assistance.

> Sometimes when we have a problem like at school, we take the LC1 Chairman and he explains to them [that we are orphans], and they give us a grace period to pay school fees. When he tells them our problems, they listen to him and they give us more time to look for that money and when we get it we take it there. (Male, 17 years)

Another LC1 supports the children when they are discriminated against by their community.

> [Our sponsor] came and asked the Chairman of our village [about the rumours], and the Chairman told her that we are good children in the village. (Male, 18 years)

3.8.6 Psychological support

Children struggling to acquire basic needs such as shelter, food, and clothing are in such dire need that their emotional concerns are often overlooked. However, the devastating psychological effects of living in such circumstances, of witnessing one or two parents die at a very young age, and of experiencing the impact of HIV/AIDS first-hand are overwhelming. In the absence of a father or mother who can guide the children through their childhood, some of the children interviewed for this study are left without anyone to talk to about their emotions, concerns, and frustrations. They reported feeling isolated, lonely, and sad.

Many respondents, however, reported having a neighbour, friend, relative, village elder, LC1, Reverend, or a sponsor to talk to about their feelings whenever the need arises. Most frequently, this person guides the children on how to behave,

encourages them to respect their sponsor, advises them not to go to discos, and tells them to persevere and be patient. One respondent explained how she is guided by her neighbours.

> They say that even if we don't have parents, we can live, so we have to cooperate, to bring these young ones well, they grow up like that. Even they tell us to study hard. (Female, 15 years)

Another explained,

> [Our neighbours] just tell us to stay like that, you know. Take it easy. (Female, 17 years)

Another respondent explained how his neighbour guides him and his brothers.

> He tells us that we should not involve ourselves in getting married because we are still young. (#14, male)

Others reported being counselled to remain in their house and on their land, and to continue to maintain good relationships with those that were friends of their parents prior to their death.

3.8.7 Gender

Differences in respondents' capacity to cope with their situations that could be attributed to their gender were not identified in this study. Although the previous example regarding the influence of age on a child's capacity to cope portrayed an older male respondent and a younger female respondent to illustrate the discrepancy between these individuals' capacities to cope, similar differences can be seen between older female respondents and younger male respondents, where the older female respondent still shows considerably more capacity to cope with her circumstances than does her young male counterpart.

Briefly examining the difference between a 17-year old female respondent who lives with her six younger siblings, including an infant sister, and a 13 year-old male respondent who lives with his two sisters aged ten and eight, it seems evident that the effect of the respondents' ages overrides that of their gender. The confidence and strength portrayed by the older respondent differs noticeably from the younger respondent whose timidity and fears were apparent throughout the interview. Although there are undoubtedly a number of confounding factors that were not explicitly identified in this study, it seems evident from observations of the 20 respondents interviewed that a child's age and their associated capacity to cope as the head of a household is more influential than that child's gender.

3.9 Stigma and discrimination

Although stigma of HIV/AIDS seems to be minimal, orphaned children who live alone are subject to judgment and prejudice as they live in a child-headed household and are often assumed to be ill-behaved and reckless. Children experience discrimination from their schools, communities, and extended family members. Below the respondents' perceived discrimination from these sources are outlined.

3.9.1 School

The majority (14 of 20) of respondents felt that they are not being discriminated against, feeling rather that they are treated the same as other children at school. They explained that if they come to school without school fees, uniform, shoes, or books, they will likely be sent home, yet made the point that this is the case for all children who come to school without the necessary requirements. As such, they explained, they do not see this as a form of discrimination towards orphaned children in particular. One respondent felt that his younger brother, who attends school, is sometimes even treated preferentially by the teachers because of his orphaned status.

> Interviewer: "Has your brother ever gone to school without the school needs?"
>
> Respondent: "Yes. There are times when the money is not yet enough and we go and plead with the teachers and they allow him to stay at school."
>
> Interviewer: "Do they accept him to stay at school because he is an orphan?"
>
> Respondent: "Yes." (Male, 17 years)

Further on in the conversation, the teachers' understanding of the boy's orphaned status is again evident.

> Interviewer: "Are the teachers treating him fairly at school or they mistreat him because he is an orphan?"
>
> Respondent: "They treat him fairly."
>
> Interviewer: "Even if he is not putting on a uniform, he is allowed to enter the class?"
>
> Respondent: "Yes." (Male, 17 years)

Similarly, another respondent described the teachers' understanding of her orphaned status:

> Interviewer: "Do the teachers chase you from school because you are not putting on shoes?"
>
> Respondent: "No, they don't, except they say that each pupil should go to schools with shoes on." (Female, 15 years)

Another respondent explained his teachers' positive relationship with him.

> They don't discriminate. Sometimes they even give me books, and they love me. (Male, 13 years)

Some respondents, however, felt that they are not treated as well as other children who have parents or adult guardians. One respondent explained how she feels her

siblings are being discriminated against at school when they are not allowed to attend meetings that are intended for parents.

> In case there is a meeting at school, they say that any kid who doesn't go with a parent will be sent home. They are usually sent. (Female, 17 years)

Another respondent spoke of his friendship circle at school, explaining that his only friends are those that are also orphaned.

> You know, for me, being an orphan... I have other students who are also orphans, those are the ones which we... everyday stay with. And you know, when we are with those ones who have their parents and whatever, that for us we feel that we're not part of that, that us when we're staying here, in that group. (Male, 18 years)

3.9.2 Community

While only few respondents reported discrimination at school, several of them expressed that they feel discriminated against or treated differently by people in their communities. Issues between the children and their neighbours related mainly to disturbances with crops, animals, and land, as well as envy of sponsorship for those being supported by an NGO. Neighbours' carelessness with their animals was of particular concern to several respondents. Respondents explained that their neighbours often allow their animals to go into the children's plantations and destroy their crops.

> The neighbours are neglecting their animals. Even if their livestock comes in our garden, they don't care, knowing that we have nothing to do. (Female, 17 years)

Evident here is the respondent's vulnerability now that there are no adults in the home who could deter such behaviour from the neighbours. Another respondent spoke of a similar experience of disturbances in their land.

> We grow maize, and we were trying to plant green vegetables, but our neighbours' children come and destroy them. We had also planted cabbages, but the neighbours' children came and uprooted them. There's a time when a dog entered in the chicken's house and ate all the chicken. (Female, 15 years).

Being only fourteen years old, this respondent finds it difficult to stand up for herself against the neighbours. Another respondent similarly explained that his chickens went onto the neighbours' land, at which time the neighbours killed his chickens. Presumably, these situations could have been avoided if the parents of these children were still alive and could protect their land and their children from such treatment.

Others reported a persistent fear of people in their community who are unfriendly towards them because they intend to take their land from the children. One respondent spoke of his neighbour from whom he cannot ask for any sort of assistance as the neighbour is not cooperative with him and his siblings.

> This immediate neighbour does not cooperate with us ... because [he] wanted to take our land. (Male, 16 years)

A different dimension of discrimination from the community arises when the children are seen to be in a better or more fortunate position than the community members themselves. While this is particularly concerning for those being sponsored by an NGO, others simply have an advantage that is envied by their neighbours. One respondent explained his neighbours' envy of his informal employment of transporting others on a borrowed motorcycle.

> Everybody does his or her own business. People in this village are very bad because when they can see somebody riding a motorcycle they just decide to bewitch you... When somebody sees you riding a motorcycle like this one, they think maybe you are going to be well off that they are. Like a woman nearby here doesn't like us at all. There is one time when [one of my siblings] went to the woman's garden and cut a sugar cane from there. She was very annoyed and came

> and poured water on our beds and took the food which was meant for the children's lunch. When I tried to talk to her and tried to explain to her that these children don't have anybody to control them, she then came and cut part of our garden plantation. There is nothing I can do because I do not hate them but they are the ones hating us. We don't have any relative here because we are like foreigners and our father just came and bought land here. (Male, 18 years)

After this incidence, the respondent told his LC1 about what had taken place, who subsequently responded through legal means.

> The Chairman came and arrested [the neighbour] and took her to police. But when the other people started talking a lot of things, then we decided to leave everything and the woman was released. (Male, 18 years)

This respondent's age, gender, and physical demeanour may give him an advantage over many of the other younger and physically smaller respondents, yet it is clear that he and his siblings are still subject to discrimination and mistreatment from the community because they lack parents to protect them. Although this respondent is almost legally an adult, it is the absence of a father or mother and the cultural and social significance of that which seems to affect the children and how they are treated by the community.

In the context of a generally poor society, it is perhaps not surprising to discover that the official assistance from an NGO also leads others to feel envious of children who benefit from such support. One respondent explained how his community has reacted to the support he receives from an NGO.

> When we are at school, some people could come and cut bunches of bananas when we are not around. And we had local goats, those ones were stolen away. When we could be at school, they come and do what they want. And now because they know that we were getting help with a European. For us here, when they see that we are talking to a European, they feel bad, and sometimes they could even take rumours that... we are smoking mbangi [marijuana] and

> drinking alcohol, and we're not sleeping in the house. We come at night. Those kind of things. They say those things because we are being helped. They envy. You know, those ones, the children have their parents but they are not getting the requirements which we get. (Male, 18 years)

Another respondent who is also being supported by the same NGO spoke of a similar situation with her neighbours.

> We grow potatoes and cassava, but the neighbours' animals usually destroy them and when we try to talk to them they say, 'These orphans have started disturbing us.' They say that because we have seen [our sponsor] assisting us. That is why we are proud. When we tried to report the matter to the Chairman, he didn't pay heed to us because we are young and the others are old people, so the Chairman just ignored us. (Female, 15 years)

These examples suggest that children living in child-headed households are discriminated against to varying degrees, whether through neighbours' carelessness with their animals or ill-treatment because of envy of the support the children receive. This is of considerable concern to the children and intensifies their feelings of loneliness, hopelessness, and sadness.

These negative impacts associated with being officially supported by an NGO can lead children to make efforts to keep their support a secret. One respondent, cognizant of the potential adverse effects they could incur if the neighbours are aware of the support they receive by the NGO, explained that he and his siblings make an effort to keep their sponsorship secret from others.

> We make sure that we keep [the sponsorship] a secret and we don't show other people that [an NGO] is assisting us. Other people think that we are getting school fees from our uncles, but we don't get school fees from them. (Male, 16 years)

Eventually, however, the children's secret of their sponsorship was inadvertently revealed, resulting in negative repercussions from the neighbours.

> They came to know about [the sponsorship] because there was a time they asked [our sponsor] who had come to check on us and she told them that she is the one who assists us. [The neighbours] just backbite us as we are passing by their house, saying that, 'Why are these being assisted?' Things of that kind. (Male, 16 years)

The children's sponsor fortunately shows understanding of the complexity of the social issues arising as a result of her assistance to the children, and checks into and/or disregards the rumours that abound about the children's behaviour. As long as the children supply her with good school reports and assure her of their good behaviour, she shows her trust in them and continues to support them.

Other respondents expressed feeling that the reaction from their community is mixed. They explained that some neighbours behave poorly toward them and do not treat them well, while others are indifferent or even supportive of them.

> Some treat us the same but there are others who treat us differently [from] children who don't have parents. (Male, 16 years)

Other children in child-headed households, moreover, reported positive experiences with their communities. In some cases, children felt that their relationship with their community is the same as it was prior to their parents' deaths. Others reported that their community members show concern by visiting and checking on them occasionally, offering guidance and advising them on how to behave.

> They take me as an orphan and they guide me when there is any problem. When I am alone and I have nobody to talk to, that is when I fear and go to the neighbours. (Male, 17 years)

This respondent felt that he benefits from the emotional and mental support he receives from his neighbours, despite his physical and material hardships. Another

respondent reported that her neighbours are very helpful, bringing food almost every week and assisting in caring for the youngest siblings. She repeatedly mentioned the support the community provides for her and her siblings. "They are trying their best," she explained (Female, 17 years). Even prior to her mother's death, when she had begun feeling ill and weak, the neighbours were assisting the family with food and caring for the dying mother. The respondents accredit their neighbours' assistance to their awareness of the children's situations and the good behaviour they display. For instance, one respondent credits the neighbours' positive reaction simply to their awareness of her family's circumstance, to knowing what is going on in her family. Another respondent reported,

> Some of those I told about the death of my parents are the ones who know that we are suffering. (Male, 13 years)

Community members also generally seem to assume that orphaned children are ill-behaved, reckless, and get into drugs and onto the street, yet when they see that such children are well-behaved and doing their best to take care of themselves, their attitudes can change. One respondent explained,

> They are seeing us as good people, because at first they were scared of us, that we would be thieves, but now I'm working, they're not thinking that. (Male, 16 years)

3.9.3 Extended family

The children's relationship with their extended families varied considerably from household to household. In some instances, family members are very helpful and appear to be doing their best to assist their nieces, nephews, grandchildren, and younger siblings that live in a child-headed household. In other instances, however, the children reported conflict with members of their extended family. In several cases, the extended family was reported to be less helpful and even more harmful than the members of the community.

Most often, conflict between the children and their extended family revolved around land.

> It's only family members who are discriminating us. These family members want to take the things which our dad left, like land, plantation, and others. (Male, 16 years)

This respondent expressed considerable concern about his grandmother, fearing that she will take the land from him.

> When family members bring confusion and want to take away our things, they [the neighbours] give me advice to do like this and that. (Male, 16 years)

Similarly, another respondent expressed concerns about his only two remaining extended family members, who are causing him to be distressed. He explained how his parents had intended for his aunt and uncle to care for them after their death, but that this has not worked out.

> They talked about it, [but] my uncles and aunties are not cooperating with me. They wanted to chase me [from the land] before even four months had elapsed and my father died, and even when my mother was still alive. (Male, 15 years)

In this respondent's clan, it is customary for children to weed the grave of the deceased father four months after his death (in the case of a mother's death, it is three months) (Alirake, personal communication, 2005). This therefore implies that the respondent's aunt and uncle wanted to take his land before he had had the opportunity to weed his father's grave. Another respondent reported his misfortune with his uncle, who came to stay with him after his father's death and began selling his matooke and eucalyptus trees which led to a conflict and the uncle's disappearance from the home.

Another respondent illustrates the complications involved in land ownership disputes between family members.

> Our great-grandfather left our father on this land. The father of our late father died when our father was still young, and so the responsibility was left with his grandfather. So he's the one who left him as an heir on this land. But now it has brought him some misunderstandings, and the aunt of our father has refused to bring back the land title... My father was left as an heir on this land. And this land was even leased. But there's a woman who stole it from me. Up to now she has never brought it back. My father used to call this woman his aunt. And she has refused to give me back that land title. But my father was left just as an heir on this land... We have nothing to do. Because we have been walking, several times going to the [government] offices in Booma, and they advised us to look for money so that they can make another land title for us. But we can't afford that money... We spent two years walking to Booma and this woman still failed to bring back the land title. And then they advised us to look for money to make another land title. (Female, 18 years)

For other respondents, although they legally hold the land title and did not report having any official disputes over this particular aspect, they reported often feeling helpless in trying to defend themselves and reported fearing members of their extended family who threaten and, in some instances, actively try to take the land from them. Respondents reported frequently being told by those looking out for them that they must not leave their land as it will be stolen from them if they do so.

> My uncles and aunties are not cooperating with me. They want to take this land. (Male, 15 years)

When asked what he fears, this respondent replied "my uncle," based on his concerns over the possible theft of his land. Another respondent expressed his worries about his family members who are not treating him and his siblings well.

> It's only my family members who are discriminating us, but the neighbours are treating us well. These family members want to take the things which our dad left, like land, plantation, and others. (Male, 16 years)

3.10 Income and sustenance

The concept of household income, especially when in reference to a child-headed household, cannot accurately assess a household's capacity for sustenance as it does not truly reflect the level of poverty or the availability of resources of a family living in extreme poverty. Because of the heavy reliance on subsistence farming and other self-sustaining methods of acquiring food, it is more appropriate to address the issue of sustenance as opposed to income, as this term encompasses both financial and non-financial aspects of survival. As one respondent explained,

> For me, if I have food, I don't mind about others like money. (Male, 16 years)

The means through which the young respondents in this study sustained themselves and their siblings included – in order of most to least frequent – growing, selling, and consuming crops such as matooke from their own plantation, receiving official support from a sponsor, official employment, unofficial employment, animals, and other projects.

3.10.1 Crops

Variations were evident in the size of respondents' land, its physical location, the availability of seeds and other materials, the children's knowledge and experience with tending to a plantation, the time available to tend to it, and the seasonal changes in climate. Despite all these variables, however, growing and harvesting crops from one's own plantation was by far the children's most common source of food and income. Most common among these crops was matooke. Beans, yams, potatoes, and maize were also grown quite frequently. Other crops grown by some of the respondents, although in limited supply and infrequently mentioned, included sweet potatoes, cassava, dodo (a green, leafy vegetable akin to chard or spinach), onions, cabbage, eggplant, sugarcane, and pumpkin.

All the respondents who grow crops on their land prioritize their use for personal consumption before selling their harvest. Some of the respondents who provide for a large family have only enough crops on their plantations to sustain themselves and have no surplus with which they can make an income. One respondent, who takes care of her five siblings and her own baby, stated,

> We only eat this food, because the soil here is not fertile enough to get surplus food for selling. (Female, 18 years)

Those who have a sufficiently large harvest, however, consume their crops first and sell the surplus from their harvest. The income they can receive from these crops ranges from UGX 1000 to UGX 3500 per week (CAD$ .66 to CAD $2.33), depending upon the quantity of crops available and how many children must be fed before any surplus can be sold. Some respondents sold their matooke publicly, either at a nearby trading centre, a weekly market, or the market in town, while others sold it to people in the neighbourhood. One respondent reported selling cooked maize at UGX 100 (CAD$ .06) a piece "to the people around" (Female, 17 years), with the potential of earning about UGX 2000 (CAD$1.33) in a week.

3.10.2 Employment

At the time of data collection, only one of the 20 respondents interviewed was formally employed. This respondent worked as a security guard for a company in Fort Portal, a one hour and forty-five minute bicycle ride (on a bicycle borrowed from a friend) away from his home. The monthly income generated from this job was variable, depending on the number of days he worked in a given month. This, in turn, depended on the weather, specifically the amount of rain in the area, which at times prevented him from being able to reach the town on his bicycle as the roads become extremely muddy and often impassable.

> [My employers] pay UGX 50 000 CAD$33 per month), but sometimes you find it's raining and I don't report to work, so at the end of the month, they deduct my money. They end up

> giving me UGX 20 000 or UGX 30 000 (CAD$ 13 or CAD$ 20). (Male, 16 years)

Although the respondent recognized that he is fortunate to be employed, noticing the many unemployed members of the community around him, he confided in us his idea to terminate his employment, noting the stress involved in the job and the little payback he receives for his efforts. He reflected,

> Now I feel I don't want the job. I want to be a farmer. Because I'm sleeping in cold, working at night, and at the same time at day. And the money paid is also little. I fear that when I have gone to work, some enemies may come and attack my brother and sister, so when I think of that I feel like leaving the job. (Male, 16 years)

The only other two forms of official employment mentioned in the interviews included employment as a hotel attendant or as a housegirl. One respondent terminated her employment as a hotel attendant after one month.

> I had left for only one month, but I used to stay here, but I went and then came back again. I came back because the person who had employed me is mistreating me. (Female, 18 years)

The younger sister of another respondent had gone to another district to work as a housegirl, but had since returned to live with her brother in the Fort Portal area.

3.10.3 Informal employment

In addition to selling crops, many respondents reported being involved in some form of informal employment. This frequently took place within the respondents' neighbourhoods and usually involved an agreed-upon arrangement whereby the child received remuneration in return for assisting in the neighbour's house or garden. Respondents reported that, in most cases, they go to the neighbour and ask for work in exchange for payment. Respondents of both genders reported digging, weeding, and planting in their neighbours' gardens. On average, they

were paid approximately UGX 1000 (CAD$ .66) for the day. One respondent reported that her younger (15 year-old) brother sometimes slashes grass in other people's compounds in order to make some income. Another respondent crashes stones for a neighbour, while another collects reeds from a swamp and sells them to others for their house construction. One female respondent reported washing clothes for other people in exchange for about UGX 2000 (CAD$ 1.33) per day. One male respondent, who is part of a household consisting of three boys, aged 16, 17, and 18, reported constructing latrines and houses for others as a source of income.

3.10.4 Animals

Although only few of the respondents owned animals of their own, such as a goat, chicken, pig, or rabbit, many respondents saw the ownership of animals as a potential source of income generation. They explained that owning an animal is beneficial either as a source of emergency aid when a child falls sick or to pay for school fees.

> When [the chickens] grow, I sell them to get little money that I add on my school fees" (Female, 15 years)

Some respondents also sell their chickens' eggs, providing an added benefit of retaining the animals. Others wait for their animals to multiply so that they can increase their potential for income.

> If this goat produces other goats, then we can sell them when we get any problem. I will wait for [the goat kids] to grow up. If they are female, I will stay with them until they produce. And if they are male, I can decide to sell them off if I have anything I need to buy. If I don't have anything I need, then I will leave those goats there. (Female, 18 years)

The income generated by one goat is relatively substantial, each goat costing around UGX 30 000 (CAD$20), whereas a chicken can be sold for about UGX 3000 (CAD$2). One respondent reported selling his pig's piglets for generating

income. One piglet can be worth about UGX 10 000 (CAD$6.66), making it a reasonably good sale.

3.10.5 Other sources of income

In addition to raising and selling animals, other methods of earning income were also mentioned. Two male respondents transport others to generate income. One uses a motorcycle to transport villagers to, from, and around the town. He rents the vehicle from someone else and pays the owner a pre-determined daily fee.

> I get [the motorcycle] from rich people who buy motorcycles and I ask him to employ me and I get a small income. We are supposed to give the owner UGX 6000 (CAD$4) [a day] but sometimes you can even fail to get this amount, this just happens by chance. On a good day, you can remain with UGX 2000 (CAD$1.33) after buying some things for use at home. (Male, 18 years)

Another respondent borrows a bicycle and uses it to transport others around the area, at times earning up to UGX 4000 (CAD$2.66) in a day. One respondent rents out one of two rooms in his home, although the income generated is irregular, inconsistent, and minimal.

> Sometimes they give us UGX 5000 or UGX 6000 (CAD$3.33 or CAD$4) a month, or if he doesn't have the money, he gives us just UGX 3000 (CAD$2). Sometimes they rent, and sometimes they go and then come back. (Male, 13 years)

3.11 Health

3.11.1 Conditions

The respondents reported a number of health conditions that afflict them and their siblings. Most frequently, incidents of fever (malaria), cough, and flu were mentioned. The respondents explained that coughs are particularly prevalent among their siblings during the dry season, when the dust from the roads darkens the air and infiltrates their sinuses. During this season, some children also develop

red or swollen eyes, and in one case "new growth in the eyes" (Male, 16 years). Ear problems, described as discharge, draining, or blood from the ear, were also mentioned. One child reported her siblings' itchy skin.

> Intestinal worms disturb these ones. Sometimes they scratch the skin when we have not given them the [deworming] tablets. (Female, 15 years)

Abdominal pain associated with not eating was also frequently reported. Headaches were quite common among the respondents and their siblings, particularly after spending considerable amounts of time in the sun. One respondent reported frequently experiencing headache and a nosebleed simultaneously.

> Myself, when I feel headache, I get nosebleeding. Sometimes it comes like four times in a month, or five. It started one year after the death of our parents. Now it's coming... at short intervals. (Male, 13 years)

Given the onset of this condition since the death of the respondent's parents, it can be surmised that the nosebleeds are associated in some way with the stress felt by the respondent bearing the responsibility of caring for his household and his siblings.

Several respondents spoke of their siblings having convulsions, the severity and frequency of which varied. Some experienced short bouts of convulsions only a few times a year, while another respondent felt heavily impacted by his convulsions, often becoming bedridden for long periods of time. "In a year, it can be like a full month," he explained (Male, 15 years).

The frequency and duration of all these conditions varied considerably, making it difficult to summarize them with much accuracy. Influencing factors regarding the frequency of conditions seem to relate to the physical environment. The rainy season is more conducive to episodes of fever/malaria, which were reported to

occur anywhere from once every two weeks to three or four times a year or at varying intervals. Conversely, the dry season brings about many coughs and headaches. Abdominal pains were reported as occurring very frequently, (once a week or more frequently), either as a result of not eating or because of missing a deworming that is to be done every three months. Reported nosebleeds happened at least once a month, often associated with working in the sun. Remarking about his brother, who suffers from repeated incidents of nosebleeds, one respondent explained,

> When he stays too long under the sun and when he does much work, that is when nasal bleeding begins. (Male, 17 years)

The accuracy of these comments may be limited, however. Some respondents struggled with the task of ascertaining the frequency with which they or their siblings experience any of these conditions. When asked to explain how many times in one year her siblings suffer from flu or cough, one respondent replied,

> That one, I don't know. Because here, there is a lot of dust when it is dry season, and you can see yourself, the dust is entering the house. There is a lot of cough and flu which is very common. (Female, 18 years)

3.11.2 Effect of health conditions on chores

The respondents' illnesses and associated weakness at times limited their capacity to carry out their daily chores. In such instances, the next oldest sibling would often do the cooking, while the other siblings shared the remaining chores. In one instance, if the respondent became very ill and unable to carry out her responsibilities around the house, her ten year-old brother would go to their late mother's friend to ask her for assistance. Another respondent explained that when he is too weak to carry out his chores he purchases some bread and he and/or his sister prepares dry tea (made with water instead of milk). This requires less energy than cooking a meal and is thus preferable during such times. It also

shows, however, that the respondent is not able to fully dissolve himself from his responsibilities as the caretaker for his siblings even when he is not well.

3.11.3 Immunizations

Almost every respondent reported that all the children in the house had been immunized although documentation for this was not sought. Only one respondent reported that he did not know whether he and his siblings had been immunized. Another respondent reported that he is certain his younger siblings have been immunized, yet he is unsure of his own status. Most respondents remembered receiving vaccinations and could report where and approximately when they last received them. They explained that they know they have been immunized because they have a scar from the vaccination. All respondents explained that they received the immunizations free of charge, often through the school they attend(ed), through an outreach clinic, the government hospital in Fort Portal, sub-county headquarters, or at a trading centre. Although most respondents could not describe with certainty for which diseases they are immunized, it seems evident from the diseases they could identify that they received all the basic vaccinations under the WHO's Expanded Program on Immunization (EPI), namely those for measles, diphtheria, pertussis, tetanus, polio, and tuberculosis (World Health Organization, 2006).

Although most of the children had been vaccinated prior to their parents' deaths, several of them received immunizations more recently, since the time that they have been living in a child-headed household. With regards to how the respondents knew when it was necessary to receive immunizations, they reported that it happened almost automatically, either through attending school, because of Mass Immunization Days, and/or because they were told to do so by a health professional. One respondent explained,

> There is a card where they keep you. If … you take [my baby sister], they tell you to come back. (Female, 17 years)

When prodded again about how exactly she knew when and where to take her siblings for immunization, she replied, "Ahhh!" and laughed, indicating it is simply basic knowledge that everyone knows. Another respondent explained,

> When we took them... we asked them, 'Are they ready to be immunized?' and those who are ready, they immunized them. Others came back, then they told us another day when they should come back. Then we took them back. (Female, 15 years)

3.11.4 Healthcare

A variety of treatment options are available in Fort Portal town and the surrounding area. The majority of respondents reported seeking treatment at a local (government-funded) health unit for most of their health concerns. Treatment is usually free at these clinics (only one respondent reported paying for his medication there), and the clinics are found throughout the rural areas, making them more accessible than the government hospital in Fort Portal. At these health units, children can be dewormed and receive treatments such as painkillers for headaches. One respondent, however, took his sister to the health unit to have her ear examined as she was bleeding from the it. Being unable to assist her there, she was referred to the government hospital. Noting that his time is limited as he is employed in Fort Portal town, he explained,

> They told me to take her to [the government] hospital, but the time when the doctors are around, I don't get that chance to go there. (Male, 16 years)

When possible, respondents preferred to be treated at the government hospital in Fort Portal, where drugs are in better supply and the range of expertise and treatment options available are greater. However, the time and cost of traveling to the hospital are often deciding factors in the children's choice of treatment. Officially, treatment is free at the government hospital, although one respondent reported being given a prescription from the hospital for which he paid at a pharmacy in town, likely because of his misunderstanding of the doctor's

instructions for taking the prescription to the hospital pharmacy where he would not be required to pay.

Children who are officially supported by an NGO have a different experience of accessing healthcare from those who are not sponsored. The NGO sponsoring five of the families interviewed for this study has made arrangements with a private clinic in Fort Portal that enables the children to be treated whenever the need arises. The sponsored children receive a card from the NGO which they take directly to the assigned clinic when they need treatment. After seeing the doctor, they go to their sponsor and she returns to the clinic to pay for their treatment. The cost of this can range from UGX 5000 to UGX 10 000 (CAD$3.33 to CAD$6.66). This system appears to be very effective, as the children can access quality healthcare without first having to go to the sponsor to ask for assistance. Only one respondent who is not being sponsored reported seeking care from a private clinic, paying for the cost of the treatment with the money he receives from selling matooke.

Other sources of healthcare and medical attention are less formal, yet they are the most accessible to the children living in more rural areas. Some respondents reported seeking medical help from friends or relatives in the area, particularly for health condition that are less serious where a painkiller may be sufficient. One respondent explained that there is a nurse who lives nearby to whom she goes when she or her siblings fall ill. Some medical attention is available at school, though this varies by school. Some children reported making an effort to attend to their health conditions at home. For instance, one respondent reported pouring water over his head when he experiences severe headaches, prior to seeking care at a clinic. Another respondent reported using herbal remedies for abdominal pain when he does not have the financial resources to seek care elsewhere. He spoke of chewing kalifoa, a grass that grows wild in much of the area, to help ease the pain in his abdomen.

3.11.5 Food intake

The children's primary source of food comes from their own land. Most respondents reported eating any crops they are able to grow in their gardens, and only supplementing it with other foods such as rice, posho (a cornmeal-based hard porridge), or millet when they can afford to, or when these are given to them by a neighbour, friend, or relative. As previously mentioned, the children most commonly grow matooke, while beans, yams, potatoes, cassava, ground nuts, and pumpkins are also not uncommon. Given the limited variety in the foods available to the children from their land, they frequently cook a meal for dinner and eat the leftovers for breakfast or lunch the following day.

Respondents reported that the frequency of their food intake varies largely by season and partly by daily routine. Nine respondents reported eating three meals a day, seven reported eating twice a day, and two reported eating only once a day. Two others reported eating two or three times a day, depending on the season. Those children living almost solely off their own land eat less frequently in the seasons when crops are less plentiful or when harvesting has not yet begun. Others reported eating less frequently when they are attending school, as they do not have the time to come home to cook something for lunch. In that case, they eat only once in the morning and once in the evening. Among those who reported eating only two times a day, supper and one of either breakfast or lunch were usually eaten. Those who reported only eating once ate their one meal at dinner time, often some time in the late afternoon, at about 16:00 hours.

Although the food available for all of these children is limited, almost half of them reported that it is enough to satisfy them. The other eleven respondents reported that they never have enough food for all of the children. With regards to how they deal with this inadequacy of food, the respondents expressed a sense of helplessness.

> No, [it is not enough], but there is nobody to ask because we know we don't have a father. (Male, 18 years)

When there is not enough food at a particular meal for everyone to feel satisfied, some respondents reported allowing their younger siblings to eat while the other older siblings go without food. This is perhaps indicative of the strong sense of responsibility felt by some of the respondents to their younger siblings. One respondent explained,

> Now these days, there is famine. Sometimes I go hungry and leave them to eat, because they are going to school. (Male, 16 years)

In other families, however, the respondents reported sharing the little food they have equally among all the children. If food is scarce, one respondent reported,

> We just remain like that. We all eat together. (Male, 16 years)

3.11.6 HIV

On the advice of local experts at Basic Health Services in Fort Portal, questions asking specifically about HIV/AIDS were avoided in the in-depth interviews with children. During these interviews, the researcher exerted considerable caution and spoke of the disease only when it was first mentioned by the respondent. Only two of the 20 respondents directly spoke specifically about HIV/AIDS. One respondent recalled a discussion with his father prior to his death, when he had explained the illness from which he was suffering and cautioned the children not to become infected as well.

> Now you know when they passed away from that [AIDS]... we conversed about that issue, and he usually told [my siblings and me] that we don't get infected. In order for us to be well and not be disturbed like this. (Male, 18 years)

He mentioned that his younger sibling had been ill over a period of time and died at the age of seven (after both parents had died).

> At this time we are three [children in the home] but we were left four, and the youngest one passed away. (Male, 18 years)

This respondent expressed confidence in his ability to prevent himself from becoming infected with the virus, yet felt concerned about his younger sister's capacity to protect herself.

> Interviewer: "Now, your sister, is she not aware of how to protect herself from HIV?"
>
> Respondent: "She knows, but I don't know, I don't know how she is taking care of herself."
>
> Interviewer: "So you're somewhat concerned?"
>
> Respondent: "Yes." (Male, 18 years)

He reported worrying about the attention his sister was receiving from boys as she grows older. He confided,

> She has grown up. There are a number of boys who are looking at her. (Male, 18 years)

Although he explained that she knows how to protect herself from the virus, he felt concerned about her ability to withstand pressures from young men who may approach her or entice her into sexual behaviour.

The other respondent who spoke directly of HIV/AIDS did so in two respects. First, she told us that one of the nine children she looks after (some of them her siblings, others her nieces and nephews that are children from her deceased older siblings) is infected with the virus.

> When our parents were still alive, they checked him and found him HIV positive. (Female, 15 years)

Fortunately, she seemed confident in the capacity of the other children in the home to protect themselves from also becoming infected.

> Our mother is the one who told us that the child is sick and we should always be careful not to use the same razor blade which he uses. I protect myself against being with men and sharp instruments. (Female, 15 years)

3.11.6 Psychological effects

Previously it was mentioned that, when faced with the challenges of acquiring even only the basic needs for getting from one day to the next, the psychological effects and emotional needs of orphaned children are often overlooked. Emphasis usually lies on the acquisition of material needs such as food, shelter, and water, to the neglect of the emotional care and mental guidance that children need as they grow up. The children interviewed for this study, however, expressed their fears and worries that have come about since they have been left to fend for themselves.

Among the respondents' fears were illnesses among siblings, being abused or raped, or intrusion from wild animals. Most pervasive, however, were the respondents' fears of theft of household possessions as well as land, crops, or animals. In some households, there are no household possessions that could be stolen, as one respondent jokingly explained, while pointing to his completely empty living room,

> The thief also goes to where these is something to steal, but now what will they steal from this house? (Male, 18 years)

Other children, however, particularly those being supported by an NGO, may own a bench or a chair that could become a target for theft. One respondent felt at particular risk of having her possessions stolen.

> There are some people who are ill-hearted. There are times when I think about chairs and… that maybe one day they will come and take them. There's a time when they came, and they took our goat which was pregnant. It was this year, just in the recent past. There are times when I think about it and I fear. And I think maybe they will come some day. (Female, 18 years)

Theft of crops and animals were also of concern to many of the children interviewed. According to one respondent, there are thieves known to steal matooke and goats which they sell at the market or to a butcher in Fort Portal town.

Second to the fear of theft was the children's fear of illness among siblings. One respondent explained,

> I get fear when [my siblings] are seriously sick. (Female, 17 years)

This fear relates to the children's feelings of not knowing how to deal with illnesses that they or their siblings experience. Convulsions, for instance, could induce considerable anxiety in the child responsible for taking care of the siblings. Potentially, the children's fears of illness among their siblings are also exacerbated by their own experiences of seeing their parents and/or another sibling die of an illness.

A few respondents mentioned their fear of wild animals, such as dogs or cows, which roam the area. One male respondent spoke of his fear of cows in his plantation when he is inside the house at night, as he perceives the cows' sounds as those of thieves.

> There are times when cows come and they stay in the matooke plantation and they make us fear. (Male, 13 years)

He also expressed his fear of wild dogs that may come to eat his goats or bite his siblings.

> Dogs at night. They can eat us, and they eat even the goats. (Male, 13 years)

Fears of physical abuse, rape, murder, or becoming infected with HIV/AIDS were also expressed by some of the children. In one instance, a respondent spoke of his fear that his brothers will be murdered while he is away at his job as a security guard in Fort Portal during the night.

> I fear that when I have gone to work, some enemies may come and attack my brother and sister. (Male, 16 years)

A female respondent who looks after nine children expressed that she fears AIDS and men.

Living in particularly vulnerable circumstances as the heads of child-headed households in extreme poverty, the respondents' fears about theft, abuse, and illness are very real. The absence of adults in the home decreases their capacity to deter others from stealing from their land and assisting their siblings when they are ill. Their vulnerability is also exacerbated by the poor physical state of most of the children's homes, where breaking in is only a matter of pushing the door open. In one particularly desperate case, a young female respondent spoke of her fear of people entering the house she shares with her ten and eight year-old sisters. The discussion that took place with this respondent is quoted here at some length, using the interpreter's words in the place of the respondent's, who was so soft-spoken, with her head hanging over her chest, that she was barely audible on the audiorecording of the interview.

> Interviewer: "Are you… afraid of anything?"
>
> Respondent: "We fear in the house because… you can even see outside, it has many holes."

Interviewer: "So are you fearing other people, are you fearing the weather, the rain?"

Respondent: "We fear people to attack us and they take off our heads."

Interviewer: "Has somebody ever come to the house while you've been sleeping?"

Respondent: "They came, they wanted to rape us."

Interviewer: "What did you do?"

Respondent: "We had to put an alarm, so the neighbour came."

Interviewer: "So … were you yelling, or how did the neighbour know she should come?"

Respondent: "We were yelling and shouting."

Interviewer: "Do you know these people that came to hurt you?"

Respondent: "They just pushed the door and they just entered."

Interviewer: "Have you seen them since then?"

Respondent: "There are some times when they come when we are still awake, and we shout, and those outside, they run away." (Female, 14 years)

This respondent's fears portray the vulnerability and helplessness that exemplify some of the children's experiences living in a child-headed household. Fears of murder, abuse, and rape permeate this young girl's thoughts. Having become completely orphaned at the age of nine (when her siblings were five and two years of age), this respondent suffers immensely from a lack of parenting, love, guidance, nurturing, and support. Her physical capacity to protect herself and her sisters is minimal, being physically small, weak, and undernourished as she eats only one meal a day.

3.12 Succession planning

To assess the extent to which Succession Planning or some variation thereof had been a part of the transition to becoming a child-headed household, respondents were asked to comment on any discussion with their parents prior to their deaths about what would happen once they are no longer around.

3.12.1 Plans

Twelve of the 20 respondents reported discussing with their parents plans for living arrangements after their parents' deaths, though none of these plans were recorded in a written will, potentially limiting their effectiveness in ensuring the children were subsequently cared for by the intended caregiver. In seven of the discussions mentioned here, the children's uncle was entrusted to care for the children after their parent(s) died. In two instances, an aunt was given this responsibility. In one family, a grandmother who had stayed with her grandchildren since the death of their parents took the children a local NGO for assistance. In two other cases, the eldest child was identified as the future caretaker for his siblings, although one of these respondents was only 13 years old at the time of his mother's death, one year after his father's death. Considering this last instance as a plan or evidence of Succession Planning stretches the limits of the very nature of the concept. It also exemplifies the desperation faced by some of these families and the continued deterioration of the extended family's support network when children are the only identifiable source of support for their younger siblings upon their parents' deaths.

3.12.2 No Plans

Despite the high likelihood that the respondents' parents were aware of their own impending death from HIV/AIDS, some respondents reported that their parents had no plans in place for who would care for the children upon their death. They reported that such discussions with their parents never took place. One respondent mentioned that there are simply no extended family members with whom their parents could have planned to leave the children. Another young female

respondent talked about confusion in her family as the reason why such plans were never made.

> My father and my mother were not staying together by the time they died. My mother had gone back to her parents and my father used to bring different wives in our house. My mother is the one who fell sick first, and when they called us to go and see her at her parents' place, our father also fell sick. We were called back from our mother's home where we had gone and then afterwards our father died. When our mother was planning to build us a new house, that is when she also became very ill and also died. (Female, 15 years)

The respondent explained that her parents' confusion and her father's behaviour of bringing various women to the house accounted for the lack of Succession Planning that occurred during this time.

3.12.3 Efficacy of plans

In a handful of child-headed households, plans that had been made while the children's parents were still alive were effectively put in place upon their death. These children lived with an adult caregiver for a period of time until this arrangement fell apart, either due to conflict or the caretaker's death, and the children ultimately became a child-headed household. In one family, the children's paternal aunt came to stay with them while their father (the aunt's brother) was still alive, and continued to stay with the children after his death. This situation remained the same until the aunt died some years later. In another family, the grandmother came to the children's home to live with them until she herself also died. Prior to her death, she arranged for the children's uncle to stay with them when she no longer could, and the uncle did so until 2004, when he left the children and moved to Kampala. In this sense, these two families had reasonably successful plans for the children's future, even if these plans only lasted for a short term.

In three other families, plans that were made were followed through only in part. In two families, the children's uncle – who had been left to take care of the children – comes to check on them regularly. He does not, however, reside in the same house with the children nor does he share regular meals with them. In another family, a friend to the late mother assists the children with food, clothes, and books, yet she also does not stay together with the children.

Unfortunately, despite planning for an adult caretaker to look after the children upon their parents' deaths, several families nevertheless became child-headed households immediately after their parents died. One respondent reported that his uncle does look after him and his siblings, yet he stays elsewhere with his own family and the children spend their days and nights alone. In another family, the assigned uncle went to the Congo while the children's father was dying, did not come to his brother's (the children's father's) burial and, to the children's knowledge, has not yet returned to Uganda. A third family was also to be taken care of by their uncle, who then reputedly became mentally unstable and left the area.

> There is an uncle, but unfortunately he ran mad and we don't know where he is. (Male, 16 years)

Two families who had made arrangements that were not followed through explained that land issues and family conflicts were the primary concern. Another respondent described a conflict with his uncle that led him and his siblings to ultimately live alone.

> Now when [my parents] passed away in the same year, [my father] left that uncle of ours to stay with [us] for about …one year and a half… and we were left with a big plantation of eucalyptus trees, and he started selling them away… there came a conflict and he stopped staying with us. (Male, 18 years)

3.13 Extended family

In exploring the phenomenon of child-headed households, where orphaned children are not cared for by extended family members and, instead, end up living completely on their own, it is useful to consider why these children end up alone instead of with their extended families. To begin exploring the respondents' experiences of this, they were asked about any extended family of which they were aware. Some respondents reported having no remaining extended family. One respondent's family is of a different tribe and had come from a different area of Uganda, implying that he has no extended family anywhere near his new home. Another respondent's father had grown up without any siblings, thus leaving no uncles or aunts that could care for the children. Some respondents reported simply not knowing the whereabouts of their extended family members. Most respondents, however, did have extended family members living nearby and gave several explanations for why they do not live with them, ranging from personal family issues, the children's ages, the family's disregard for the children, conflict over land, and the presence of the extended family's own family.

One respondent explained why he and his siblings could not live with his only remaining relative in the area, his grandfather.

> Our grandfather had so many wives so we cannot manage to go and stay in such a big family. (Male, 18 years)

Another respondent spoke of a grandmother who lives in a different sub-county, with whom they cannot stay because they are living on their father's land.

> Our parents found themselves in this area, so our grandmother could not accept to come stay with us. (Male, 16 years)

The extended family's disregard for the children's circumstances was frequently expressed as a reason for their refusal to care for the children. Respondents explained that their family member has no time for them and that their relatives

refused to stay with them. Another respondent who has a 26 year-old cousin nearby explains the difficulty in staying with him.

> He has his own family, and you'll find that I may not cooperate with the wife. (Male, 15 years)

One spoke of her grandfather's reluctance to have the children stay with them.

> Our grandfather also has his own family. He told us we should stay in this house. (Female, 14 years)

Referring to her grandmother, the respondent further explained that,

> They told us we should secure our land or else they'll take it away from us. (Female, 14 years)

3.14 Transitional arrangements

Six of the 20 families did not become child-headed households immediately upon the death of their parents. Instead, the children lived with extended family members in transitional arrangements which lasted anywhere from one week to eight years. In three cases, the children's uncle came to stay with them, one for two months, another not staying regularly but alternating visits with the children's older sister, and another staying for one and a half years until conflict between him and the children over household and land possessions ended the arrangement. In two families the grandmother came to live with the children, one for only one week until she returned to her own home, and another for eight years until her own death in 2002. One aunt came to live with the children until her own death a few years later. The rarity and their haphazard nature of these arrangements again demonstrate the need for better planning with the children, their parents, extended family members, and the community prior to the death of their parents.

3.15 Transition to child-headed households

Living in or being the head of a child-headed household was expressed as a challenge by all the respondents. Many of the respondents explained that living without any parents or a guardian is very difficult, particularly at first.

> It is difficult, but after getting used to it, it becomes easy. Because, before getting used [to it], you find it difficult and you ask yourself 'What can I do, what can I prepare?' But after getting used [to it], when you wake up in the morning, you tell [the siblings] to do different home cores, for example you tell one to sweep the courtyard and you tell the other one to wash the dishes, and for me, I go to the garden. Then, after coming from there, as they have collected water, I just cook for them and they eat. (Female, 18 years)

Another respondent explained that it was difficult at first to be a child-headed household before receiving assistance from an NGO. Referring to his younger brother, who was HIV-positive and died at the age of seven years, he reported,

> It was more difficult [at first]. Like when we have no help yet from [our sponsor], that is when we would fall sick with the other brother here, and then we see we even could not get treatment when we were at the hospital. When we could fall sick, we couldn't even study well at school. (Male, 18 years)

The decreasing difficulty of looking after a household over time may be explained, in part, by the natural developments that occur as children mature physically, mentally, and emotionally, increasing their capacity to cope with their responsibilities. In addition, almost all the respondents noted that being the head of a child-headed household becomes easier over time as they become more accustomed to their roles. At first, "it was difficult, but now I'm used to it" (Female, 17 years). As time passes after initially becoming a child-headed household, the children adopt more routines, learn to work together to carry out their responsibilities and chores, and learn how to better care for one another.

3.16 Transportation

Despite the availability of transportation in the form of motorcycles, bicycles, or minibuses within reasonable distance of the children's homes, the majority of respondents reported reaching most places on foot as they cannot afford the cost of transportation, which ranges from approximately UGX 500 (CAD$.33) for a short distance to UGX 1500 (CAD$1) for a reasonably far distance by motorcycle or minibus. With the exception of one respondent, who was given a bicycle by his sponsor which he uses to transport himself to school, all the respondents reported walking to school everyday, which could take up to 1.5 or two hours. When accessing healthcare, such as a local health unit or the government hospital in Fort Portal town, respondents again reported walking to reach the clinic. A notable exception to this is for those who are supported by an NGO, as the director of this NGO often assists the children by either transporting them in her own vehicle or by providing them with enough money to return home on public transport. The few respondents who own a bicycle reported using this to transport their younger siblings to a clinic or hospital when they require medical treatment.

3.17 Future thoughts

Respondents were asked about their plans for the future, what they envisioned, and how they would like it to be. A few respondents expected that they will simply continue to suffer as they are now, anticipating that things are unlikely to change and that they will continue to have little access to education or other opportunities to improve their situations. The majority of respondents, however, wanted to become employed in an occupation that requires formal education. They most frequently expressed an interest in becoming a teacher, doctor, or nurse, while one mentioned he would like to become a pilot and another a Parish priest. All the respondents agreed that in order to achieve their goal, should the have the opportunity to attend school, they must work hard, study diligently, behave well, and persevere.

A few respondents expressed uncertainty about what their future holds and did not want to make any predictions. One respondent explained that, because she is not in school, it is difficult for her to come up with a plan for her future.

> At this time, I don't have [anything I would like to achieve in the future]. I would be thinking that I become such and such a person in the future, but I don't think I have anything I can think about because I'm not in school, that I continue with my studies. I don't have anything I'm thinking about, except if there's any plan God has for me, then I don't know. (Female, 18 years)

Another respondent, although unsure of what the future holds for him, mentioned a commitment he and his brothers had made to work together to secure a good future. Perhaps indicative of the strong sense of family, camaraderie, and responsibility that often exists between the respondents and their siblings, he explained,

> We all agreed that when the situation allows, after school, we shall be doing something from where to get school fees. (Male, 17 years)

A few respondents spoke of their intent or desire to use their land to secure their future, either through growing crops or raising animals that can be sold. After indicating that she has some hope about her future, one respondent explained that her hope lies in her matooke plantation and her goats.

> Now, in matooke, if we look after it properly, it can give us much yields. If we look after [our goats] properly, we can sell and get money. (Female, 17 years)

Another respondent spoke specifically of his desire to live off the land.

> I have plans, if I get money and my brothers are also working, I can buy a land such that we expand. For my case, I want... in future to be having cows. I purchase agriculture

so that my sister and brother can continue with their studies.
(Male, 16 years)

A number of respondents spoke of their intention or desire to find employment. In some instances, they were not specific about the type of employment they sought, stating only that they would like any job that could be of assistance to them. One respondent wished to own his own motorcycle that he could use for transporting others instead of using other people's motorcycles for this purpose as he does now. Another respondent who is training as a car mechanic in a garage, hoped to find employment upon completing his training. Finally, another respondent expressed uncertainty about his future employment, yet said that he hoped to start a small business of selling items such as clothes or shoes in the market.

3.18 Institutions

To explore the feelings of children living in a child-headed household about institutional responses to the orphan crisis, they were asked to comment on their preference of remaining in their homes or going to an orphanage if they were given the opportunity. Only few respondents reported a preference for going to an orphanage. One respondent said this was because of the difficulty of paying the monthly rent for the house in which she lives. Others who responded favourably to the hypothetical option of living in an orphanage reported that they assumed that material needs such as mattresses, shoes, clothes, food, and access to healthcare would be catered for in such a setting. Others also cited their fear of being alone and the loneliness they feel living in their homes as reasons for preferring to live in an orphanage.

For the most part, however, respondents expressed a strong preference for staying in their home rather than going to an orphanage. The most frequently cited reason for this was the necessity of staying on the land in order not to have it stolen or taken from them. The respondents expressed an acute awareness of the potential for land loss should they leave the land to go elsewhere, and this was a risk that they did not want to take. The associated threat of having their household

possessions stolen if they leave the home was also a part of this preference for staying where they are. In addition, respondents expressed their desire to stay together with their siblings, and not to get 'scattered' by possibly ending up in different institutions. Remaining together as a family unit was of importance to them. They worried about what would happen to the rest of their siblings should only some of them be taken up by an orphanage, and expressed concerns over having nowhere for the other children to stay. One respondent explained that he and his brothers are not living with their uncle not only because the uncle has his own family, but because they also have their own home. As previously mentioned, some respondents also felt they have a cultural responsibility to remain on the land they inherited from their parents.

Other respondents reported wanting to remain on their land because of the positive relationship they have with their neighbours, who treat them well and, at times, assist them with material support such as food and other needs. Because of this, the respondents see no reason to leave their land to go elsewhere. Two respondents gave a mixed response, one suggesting that, given the option, he would allow the younger siblings to go to an orphanage while he and the other older siblings should stay on the land to protect it.

> They can't take me, [but they could] take those other children, because if they take me, nobody will be responsible to look after our land. (Male, 18 years)

Similarly, another respondent suggested that his siblings could go to an orphanage while he remains at home in order to prevent the land from being taken by his neighbours.

3.19 Children to care for themselves

In some instances, although a member of the extended family is available to look after the children, support is withheld from them. In some instances, the children are either considered to be old enough to take care of themselves and do not need

an adult to look after them. One respondent explained that his family members discontinued visiting him and his siblings when he turned 15, presuming this absence might be because "maybe they know that we have grown up by now" (Male, 16 years). Another respondent explained that only his youngest sister is being assisted by his uncle, while he remains without support.

> He said that [we] are old enough, [we] should look after [ourselves]. [Also, my uncle] was driving his vehicle [for money], but now it broke down. (Male, 16 years)

In one instance, the children's uncle pays for their school fees, but does not provide them with any additional support. The respondent thinks this is because of his uncle's belief that the land on which the children live is sufficient to sustain them.

> He knows that as long as we have this piece of land, we can sell matooke and sustain ourselves. (Male, 17 years)

Others are told by extended family members and people within the community that they should stay on their land to prevent it from being taken by others.

Chapter Four: Discussion

Combined, the quantitative and qualitative data collected for this study provide insight into the circumstances in which children in child-headed households live, the challenges they face, the support they receive or require, and the resilience they portray as they cope with their challenging situations. A number of issues pertinent in the study of child-headed households have come to the fore.

The magnitude of the phenomenon of child-headed households in this western region of Uganda is staggering and these children's needs are urgent. In the following, qualities that contribute to the children's capacity to cope with their situations are identified, and the noticeable reduction in stigma against HIV/AIDS-affected families is observed. The loss of important knowledge transfer from one generation to the next and its implications for the children's health and the society's future are considered. The importance of land for stability and income is highlighted, and the multifaceted nature of official and unofficial support provided for children in child-headed households is explained. The apparent contradiction between the children's and the LC1s' perceptions of effective support systems are investigated. Some explanations that may account for the reasons why children live in child-headed households instead of with extended family members are proposed. Future implications of the phenomenon of child-headed households are predicted and the LC1s' encouraging optimism for the fate of children in child-headed households in the future is noted.

4.1 Magnitude of child-headed households

Evident in the staggering numbers of child-headed households reported by the LC1s is the urgency with which this situation must be addressed. Early predictions made by Foster and his colleagues (1997) about the rise in the numbers and proportions of child-headed households over the years seem to have materialized. Informed estimates suggest that 2127 (95% confidence interval: 1613 to 2641) households in Kabarole District, or the equivalent of two percent of

the overall number of households in the district, are headed by orphaned children under the age of 18 years, the majority of which have come into their present situation because their parents died of HIV/AIDS-related causes. These proportions may even be slightly underestimated, given that the household size used for these calculations is notably small and, if using a larger household size that reduces the overall number of households reported for Kabarole District, child-headed households would make up proportionately more households than reported here. In addition, the transient nature of some child-headed households may also skew these numbers. As Foster and his colleagues note,

> As child household heads reach 18 years old, their household by definition becomes adolescent-headed. (Foster et al, 1997, p 158)

The inclusion criteria of this study thus necessarily exclude adolescent-headed households, although they may have been child-headed households for years previous. Having been estimated at a minimum of four child-headed households per thousand households (or .4%) by Foster and his colleagues in 1997 (Foster et al, 1997), even these low estimates indicate an increase in the number of child-headed households over the previous decade. Also of note is Foster and his colleagues' (1997) observation of a higher prevalence of child-headed households in rural as compared to urban areas which was similarly discovered in this study but found not to be a statistically significant difference when overall population sizes were taken into consideration.

LC1s also estimated that approximately 13 112 children, or 10 percent of the population in Kabarole District, are orphaned. These estimates likely represent only a slight inflation, given that the 2 million orphaned children reported to live in Uganda constitute eight percent of the overall country population of 24.4 million (Uganda Bureau of Statistics, 2006).

4.2 Urgent needs

The children's most urgent needs as reported by the LC1s are consistent with other studies that have assessed the needs of children orphaned by HIV/AIDS in Uganda. The needs identified include "shelter, school fees and equipment, food, bedding, clothing, medical care and provision of care to younger siblings" as the most urgent problems faced by orphaned children (Ntozi et al, 1999). The children's descriptions of their lives, their fears, and their concerns underscore this urgency as they portray a reality beyond that which can be elicited through statistics. The problems they face and the burden of responsibility they carry are phenomenal. As the LC1s pointed out and the child heads of households confirmed, these children lack even the most basic needs. In addition, the absence of guidance and emotional care affects their wellbeing and causes concern for their impact on the future of the country.

4.3 Coping

In this study attempts were made to identify key qualities or characteristics of child heads of households that contribute to their capacity to adequately cope with the challenges they face, distinguishing them from others who are less able to manage with their overwhelming circumstances. A number of factors, such as the children's age, the age gap between the children in the households, their behaviour, and the level and nature of the support they receive were identified as important factors. Older children who tend to be physically, mentally, and emotionally more mature than their younger counterparts seem to be better able to cope with their circumstances than those who are still very young. In addition to these obvious characteristics, several factors may contribute to the influence of age on their capacity to cope. It is likely that older children may have been living in a child-headed household for longer than their younger counterparts. This is important because the passing of time seems to lessen the difficulty of living in a child-headed household as the children learn effective coping strategies and become accustomed to their new reality. Children's physical stature also seems to have an effect on children's capacity to cope, as their perceived capacity to

physically defend themselves from others reduces their fears. This factor also seemed to influence their capacity to pursue varying types of labour and employment which are less suitable for smaller, physically immature individuals, who lack the physical strength to carry out some forms of labour.

Of interest is the observation that the influence of age seems to override any differences in gender that may impact a child's capacity to cope. Although efforts were made to be sensitive to gender influences in this regard, such differences were not easily discernible. This may be indicative of the unquestionably dire circumstances of children living in child-headed households, which negate any preconceptions about the role of young women or men in the care of children and the maintenance of a household. While in intact households differences in roles carried out by either gender can often be easily identified, the children's burden as they take on the responsibility of looking after their siblings and their household seems to be of such magnitude that they are required to carry out all tasks, regardless of their ascription to either gender, and to make efforts to maximize their capacity to cope with their situations. The effect of gender on this capacity was thus not apparent.

In addition, while internal displacement and the mobility of extended family members seem to intensify orphaned children's risk of not being cared for, the community's response to the children's situation seems also to be instrumental in determining the children's experiences and capacity to cope with their extenuating circumstances. The small gesture of regularly visiting and checking in on the children, offering them guidance, mentorship, and counselling, seems to have a tremendously positive impact on the children.

What is evident in this list of identifiable factors that influence children's capacities to cope is the limited extent to which the children can influence or have control over these factors. Clearly, their age and gender, as well as that of the others in their home, are circumstantial and cannot be influenced by the children.

It would seem that the amount of support they receive from family members, neighbours, sponsors, and LC1s is also beyond their control. Yet the child respondents and the LC1s mentioned that children's good behaviour has at least some influence, even if minimal, on the relationship between the children and those who may either support or shun them. Although good behaviour by no means guarantees assistance and support, it can facilitate the children's maintenance of existing support and discourage others from discriminating against them. As some child respondents pointed out, if they work hard and do not participate in reckless behaviour, thereby contradicting a commonly-held perception among many communities of orphaned children as careless and difficult to manage, others will take note of their efforts and treat them with respect. This implies that the encouragement child heads of households receive from neighbours, extended family members, and sponsors to behave well and persevere in their efforts is important in contributing to the children's overall wellbeing and capacity to cope with their situations.

4.4 Stigma and discrimination

In many countries of sub-Saharan Africa, children living in child-headed households would face not only the material challenges that accompany their circumstances, but also a notable element of stigma associated with their parents' deaths from HIV/AIDS-related causes. Of interest in this study is the observation that the stigma experienced by the children was not associated with HIV/AIDS, but rather stemmed from issues such as land and the support received by children. The majority of child heads of households felt that they were being treated the same as other children, and had noticed little or no difference in others' behaviour towards them since the death of their parents. LC1s, similarly, felt that stigma was of little concern, mentioning rather the government's mismanagement of funds as the culprit in efforts to assist orphaned children. This may be indicative of Uganda's unique position within sub-Saharan Africa, which boasts of relative openness with regards to HIV/AIDS, widespread awareness about the disease among its citizens, and a discernible decline in the stigma often associated with

the disease. These findings support the suggestion that discrimination of those infected with and affected by HIV has declined noticeably in Uganda, when compared to the surrounding countries that are also marred by intense AIDS epidemics (Green, 2003).

4.5 Responsibilities of child-headed households

This study has highlighted the huge burden children heading child-headed households face and the numerous adult responsibilities they assume as they make efforts to secure their family's wellbeing. It has also shown that even young children in child-headed households take on numerous physically demanding tasks that would otherwise be the responsibility of an older sibling or a parent in an intact household. Some of the children reported learning how to carry out these responsibilities by observing their parents, particularly their mothers, prior to their death. Others felt they simply learned how to do certain chores as natural factor of growing up. Nevertheless, a lack of important transfer of knowledge and skills from parents to their children, which jeopardizes the capacity of these children to learn valuable agricultural techniques, caretaking methods, and a multitude of familial and societal values and customs, is evident. Children expressed a need for advice in tending to their plantations as their parents had died before having the opportunity to guide and teach them in this regard. Although comparisons between the children's crops and those of adults in their neighbourhoods were not officially made, it is presumable that their limited knowledge in agricultural methods may have the effect of limiting their capacity to grow a variety of nutritious foods, impacting their health and wellbeing. As parents die before they can impart essential customs and traditions to their children, moreover, important societal traditions are undermined and unintended social change may result.

4.6 Health

The health implications associated with the stress and anxiety felt by children responsible for heading a child-headed household are concerning. The onset of illnesses and health conditions that developed with increasing frequency after the

death of a child's parent(s) are perhaps indicative of emotional and psychological stresses being expressed physically through ailments such as frequent headaches and nosebleeds. These are further exacerbated by the children's minimal experience and knowledge of health conditions and their limited capacity to access medical treatment and healthcare.

4.7 Land

For families who may have little or nothing else on which they can rely for income, land ownership is of considerable value. This has also surfaced as important for children living in child-headed households, signifying to them a sense of stability as, regardless of what other obstacles they may face, they can grow crops for home consumption or income generation. All the respondents in this study who own land reported growing at least one type of crop. The benefit of owning land was also particularly influential in the respondents' desire to remain where they are rather than opting to move to the home of an extended family member or live in an institution. This is worth noting as it demonstrates the children's awareness of the value of land ownership which they feel should be safeguarded at all costs, regardless of what difficulties may be associated with living in a child-headed household. It further implies that it is critical that children in child-headed households be supported in efforts to maintain their land and safeguard them from others who may make attempts to take it from them.

4.8 Support

Varying levels of support, methods of accessing, obtaining and maintaining support, and the complexity of its impact were considered in this study. It is interesting to note that, although many LC1s felt that the government initiatives are effective support systems for orphaned children, when asked what they themselves could do as leaders of their communities, few of them proposed that they should assist orphaned directly. This may be indicative of their perception that higher government structures hold the resources to make such contributions to the welfare of children living in child-headed households, but that they

themselves lack the capacity to be of any notable assistance, at least materially, to these children. The children, however, felt that the LC1s could play an instrumental role in protecting and supporting them at times when they most needed it.

The children's experiences of receiving support varied quite considerably between the 20 respondents, some of them feeling well supported by their schools, extended family members, and neighbours within their communities, others not perceiving any notable difference in their relationships with others since they became a child-headed household, and other respondents perceiving considerable stigmatization and discrimination from those around them. Although the small sample size used in this study does not allow for conclusive statements to be forwarded in this regard it can be observed that, for the most part, children seem to feel better supported by neighbours and members of the community than by members of their own extended family. The experiences of some of the children interviewed show that some extended families, apart from not assisting the children as they cope with their daily struggles in child-headed households, in fact neglect the children and even behave discriminatorily against them. Although this was not experienced by all the children interviewed, and some children commented about the support and assistance they receive from them, difficulties with extended families over issues such as land caused substantial anxiety for some of the children. Because of the extended family's potential to offer much-needed support to their orphaned relatives, this finding is considerably concerning.

Of particular interest, moreover, are the LC1s' perceptions of the extended family as an effective support system for orphaned children. Although reflective of a general view among the population that it is the responsibility of the extended family to care for orphaned children (Ntozi & Mukiza-Gapere, 1995) and not surprising given the extended family's traditionally unwavering support to orphaned children, this view differs quite considerably from the experiences of

children living in child-headed households. The extent to which this is significant is not clear. By identifying child-headed households as research subjects, orphaned children who are well supported by their extended family members are almost by necessity excluded as they most likely live with their relatives and therefore do not meet the inclusion criteria of this study. Nevertheless, the inability of an extended family to physically take their orphaned nieces, nephews, and/or grandchildren into their care is distinct from being unsupportive and discriminatory towards them. That is, although an extended family may not have the capacity to assist their orphaned children through caring for them in their homes, lacking the space, time, and resources to look after additional children, they can nevertheless make an effort to support the children in their own child-headed homes, whether materially or emotionally or a combination of both.

The absence of this support as perceived by the children living in child-headed households may be symptomatic of a change in the family structure that has, for generations, been the safety net for orphaned children. Evidence from this study suggests that, in part, the presence of the extended family's own family and the importance of staying on one's own land explain why children live in child-headed households. The observation that the children's extended families do not have the time, money, space, or resources to care for children in addition to their own signifies a shift away from the traditional support structures upon which families in sub-Saharan Africa have depended for decades. This supports findings of research carried out by Foster and his colleagues in Zimbabwe (1997), in which they identify various reasons that explained why children live alone in child-headed households rather than with members of their extended family. In their study these authors found that, in some instances, the children did not know of any relative that lived nearby, in one instance it had been their mother's dying wish that they remain alone, in others the members of the extended family refused to care for the children, and in other instances it was the children who refused to live with their extended family. They mention that some extended family members did not want to live with their orphaned relatives because,

> The relatives had their own life to live, they had no space, they were in need of care themselves or they had no love for the children. (Foster et al, 1997, p 161)

This was echoed in the present study and reflects the complexity of the nature of support from extended families in the care of orphaned children.

Also interesting is the contradiction between the LC1s' suggestion that government initiatives are effective support systems and the children's perception of the inadequacy of the government's response to their situation. This exposes a disjoint between the intentions of government initiatives to assist vulnerable populations in their jurisdictions and the extent to which such efforts trickle down to those in most dire need. Although government and non-government initiatives do exist in the region, the intended recipients or targets of the assistance do not necessarily always see what is intended for them.

4.9 Implications for the future

This study has described the incredible hardships children living in child-headed households endure and the challenges they face on a daily basis. Although the HIV/AIDS epidemic in sub-Saharan Africa is already affecting all of civil society and wreaking considerable havoc throughout the continent, some of the long-term effects of this disease have yet to be seen. Raising a generation of orphaned children without guidance and parental care will undoubtedly affect the future of society, politics, and civil life in this region for decades to come. As Stephen Lewis, UN special envoy for HIV/AIDS in Africa reported in the United Nations journal, Africa Recovery, if the orphan crisis continues on its current trajectory, the future of sub-Saharan Africa will be grim.

> You have a society where kids haven't been to school and therefore can't fulfill even basic jobs... a society where a large proportion can have anti-socialist instincts because their lives will have been so hard. You have a generation of children who will be more vulnerable to exploitation and to

> disease because they won't have the same sense of self-worth. (Lewis in Fleshman, 2001, p 1)

Despite this grim picture, some optimism about the children's future is discernible. It is both encouraging and heartbreaking to note that many of the children living in child-headed households, with very limited access to basic needs and even fewer opportunities for receiving an education, nevertheless have ambitious aspirations for their futures as they strive to become well-educated professionals. Their desire to be able to properly care for their siblings and potentially their own families in the future is strong. Moreover, although LC1s generally tended to add conditions to their responses about the hope for the future of orphaned children by noting that they felt there was hope for them only if the government takes the initiative to address the issue, their relative optimism is encouraging and important for future efforts to address this phenomenon.

4.9 Future studies

Future studies examining the phenomenon of child-headed households could explore a variety of interesting issue that arose and were not fully addressed in this study. The discrepancy between community leaders' perception of the role of the extended family in orphan care and the support experienced by orphaned children could provide interesting analysis. In this study, LC1s overwhelmingly cited the extended family as an effective and essential support system available for orphaned children which is in sharp contrast to the responses of a number of child heads of households, who expressed considerable concern about their extended family. An investigation of what may be a deterioration of the culture of the extended family, a structure that has traditionally been the mainstay of orphan support throughout much of Africa for many years, as well as an analysis of the communities' perceptions of this evolving dynamic could be of interest.

In addition, thoroughly investigating the natural coping mechanisms of children who find themselves in child-headed households could contribute further to the findings generated from this study. Although an attempt was made in this study to

uncover some of these mechanisms, detailed research examining specifically what distinguishes children's capacities to cope with their circumstances could be valuable.

4.10 Proposed interventions

Recommendations for how best to assist orphaned children have been made by numerous researchers and organizations studying the circumstances within which such children live. Underscoring the importance of addressing this problem, the German Technical Cooperation (GTZ) notes that,

> Any meaningful development of the nation needs to take note of the fact that young people constitute the major human resource of Uganda. (GTZ, 2003, p 1)

Plan International offers important guidance and recommendations in this regard. The essence of this organization's approach to the situation of child-headed households is to work collaboratively with children and their communities to recognize and work with their capabilities for long term initiatives rather than promoting "short-term emergency that can be resolved with a short-term injection of resources" (Plan Finland, 2005, p 1). It emphasizes the need to find the appropriate balance between offering reactionary, short-term relief interventions to address the children's most urgent needs, and working with communities to initiate development interventions that have a long-term focus and build on the strengths of both the children and the community as a whole. Attention is drawn to the distinction between 'child-focused' initiatives instigated *for* children and 'child-centred' initiatives developed *with* children by building on their natural coping mechanisms. These approaches differ not in *what* is being done to assist the orphaned children, but rather in *how* this is being accomplished.

The organization also recognizes the children's emotional needs and suggests that child counsellors assist the children in strengthening their own natural coping mechanisms, dealing with the loss of their parents and trying to find meaning and optimism about their lives. At the same time, it cautions strongly against assisting

the children so much that they end up in more advantageous positions than the other members of their community. It warns,

> Do not elevate the quality of life of CHHs [child-headed households] beyond that of their neighbours, creating jealousy, which repels volunteers from the CHHs, and also makes CHHs vulnerable to attacks from thieves. (Plan Finland, 2005, p 6)

This addresses precisely the situations addressed in this study that outlined the envy of neighbours that resulted from the children's association with an NGO. This is a particularly important recommendation that should guide and influence any initiatives developed to address the situation of child-headed households. Support must necessarily be community-oriented and not based on supporting individual children without community involvement.

Throughout this study, an attempt was made to identify the most important variables that must be considered in the design or expansion of initiatives that support child-headed households. Building on existing recommendations and basing ideas on the data collected for this study, suggestions about how the phenomenon of child-headed households specifically in Kabarole District can be addressed are made. The intention of this study was not to develop completely new ways of addressing the plight of orphaned children, but rather to recognize the tremendous efforts that made by NGOs, CBOs, and individuals to address the situation of orphaned children and to build upon, guide, and strengthen support mechanisms that are already in place. The recommendations included here involve all levels of society, from families, to communities, to parishes, districts, and national government initiatives. Preventive measures to avert the situation of child-headed households altogether must be combined with reactive measures that address the situation that already exists.

4.10.1 Extended family

Involvement of the extended family in the care of children orphaned by HIV/AIDS is critical. The history of sub-Saharan Africa over the last two decades confirms that the extended family has been most effective in supporting children who lose their parents prematurely. The role of the family in addressing the situation of child-headed households should go beyond the traditional coping mechanisms of automatically taking orphaned children in upon the death of their parents as this has been shown to be deteriorating over the years. It is important for extended families to be involved in planning for the children's future prior to their parents' deaths. They should be assisted in their efforts to provide support during the critical stages of the parents' illness, and in following through with the family's plans upon the death of the parents.

Integration of Succession Planning into communities should also be prioritized. This could go beyond the basic components of creating a will and developing a memory book to include a detailed plan about the children's future after their parents' deaths. Because of the progressive nature of HIV infection to full-blown AIDS, parents who are infected with HIV will likely notice that they are losing their strength and are becoming progressively sicker over time. Families are thus usually aware of their impending death and have some time in which to plan the children's future. During this time, families should be encouraged to discuss in detail what options the children will have after their parents die. Possible future caretakers, preferably members of the extended family, such as the children's uncles or aunts, need to be identified. Grandparents may be an alternative if uncles or aunts are unavailable, although they may also die reasonably soon and may not be able to see the children through until adulthood. Barring the availability of an extended family member who can care for the children after their parents die, a close family friend can be entrusted to take on this role.

It is important that, in any such discussions between the parents and their children about the children's future, the intended future caregiver be included in the

planning. As the respondents in this study showed, telling a child that his uncle will look after him after his parents' deaths is almost futile when the uncle knows nothing of this arrangement, does not agree with it, or is otherwise not included in the discussion. Undoubtedly such proposed arrangements are complicated by a number of important considerations, such as where the children will live after their parents' deaths. The issue of land inheritance, ownership, and maintenance is crucial in this regard. Because of the value of owning land in a society where subsistence farming is the predominant method of sustenance, children should be encouraged to remain on their land upon their parents' death (Foster et al, 1996). This ensures a valuable source of security for the children's future, yet inevitably also adds complexity to the arrangement, as the intended caregiver will also likely feel a need to remain on his or her own land.

Finding a compromise to this dilemma is challenging. One option, albeit not ideal, is for the younger children to live with the intended caregiver while the older children stay in their own home. This could provide the younger children with much-needed emotional and behavioural guidance, while potentially providing them with a reasonable amount of nutritious food they would not have access to if remaining in a household headed by a child sibling. What is not particularly desirable about this option, however, is its disruption of the children's relations with their siblings.

This dilemma points to the need for individualizing the response to this phenomenon of child-headed households for each family that is affected by it. As was evident in the child respondents' descriptions of their ability to cope as heads of households, their age is one factor that affects their ability to cope with the challenges they experience on a daily basis. Children who are orphaned at a later stage, when they are perhaps in their mid to late teens, may be capable of doing reasonably well on their own given sufficient external support from extended family, neighbours, and friends. In such instances, emphasis should be placed on supporting them in their existing homes, so that they can use and maintain the

land they inherited. Younger children, however, struggle considerably in such circumstances and may need to be cared for by extended family members whenever possible. Although this breaks up the families and separates siblings from one another, it may be a reasonable transitional solution that can see the younger children through until they can return to live with their siblings.

4.10.2 Community

Close involvement of the community in addressing the phenomenon of child-headed households in their villages is critical and can have a positive effect on efforts to mitigate the impact of HIV/AIDS on orphaned children. The communities' lack of awareness about the situation of child-headed households was reported by some LC1s as the reason for their limited or negligible involvement in addressing orphaned children's plight. A necessary first step in gaining the communities' involvement in and support for children living in child-headed households is therefore to raise awareness about these children locally within villages, regionally at the sub-county level, and nationally. Bringing together the community to learn about the situation of child-headed households in each of their villages also offers an opportunity to develop community networks and support.

Critical to raising the communities' awareness are the individuals who carry out this task. In addition to having a sound understanding of the particular circumstances that characterize a particular region, those assigned to increase communities' awareness of the situation of child-headed households and to motivate them to become involved in addressing their plight should be recognized and respected members of the communities. They must be close enough to the communities to be recognized as trusted members of that community, yet at the same time sufficiently removed from them to be regarded as influential and important. Government officials at the sub-county level, or LC3s, suitably fit this description. As leaders at the sub-county level, LC3s are recognized as members of the community yet garner the respect of community members because of their

position as government officials within the district. Acquiring their understanding, support, and motivation is thus instrumental in engaging the communities in efforts to address the phenomenon of child-headed households. In order to gain the LC3s' interest, the district director, or LC5, could urge the LC3s to take the initiative to address this important problem in their sub-counties. To do so, the LC5 should hold meetings with the district's LC3s to inform them of the situation of child-headed households and present them with possible strategies for engaging the communities in addressing this problem within their jurisdictions.

The attention of LC1s, community leaders, and other members of the community should be garnered. The responsibility of addressing the situation of child-headed households locally then resides in small networks of individuals at the village level. An LC1's role should be that of a liaison between the village level and the sub-county's LC3. As LC1s are representatives of their communities at the local level, this could be easily achieved. LC1s should offer guidance and resources to the communities as they develop, implement, and assess their initiatives and monitor the transparency of their initiatives. Members of the community can then come together to form committees to develop appropriate initiatives to address the situation of child-headed households within their village. This will include enumerating the orphaned children and those living in child-headed households to give them an accurate picture of the situation they face in their own village. Detailed needs assessments can be carried out, ascertaining the children's availability of food, housing/shelter, bedding, school fees and scholastic materials, health concerns, and psychological needs.

These committees should be encouraged to make efforts to cater to the children's most urgent needs. Because of the widespread poverty throughout much of the region, this is particularly challenging for communities that are generally poor. As Foster (2002) points out, this does not mean that communities can turn a blind eye to the needs of orphans. "Community coping responses often involve the poor helping the destitute," he suggests (2002, p 1908). Creativity and enthusiasm in

addressing this issue can assist in the development of feasible methods of addressing the children's most urgent concerns.

To address the children's need for food and nourishment, communities can establish communal gardens in their villages, either on common land in the village or on the land of a school nearby. An agreed-upon proportion of the harvest can be allocated to the orphaned children and those living in child-headed households within the village, and the remainder shared among those participating in its development and maintenance. Seeds, materials, and land can be provided by well-wishers, the government, or other NGOs in the area. Given well-developed proposals and clearly identified community plans, the attainment of these basic necessities for the initial creation of a garden is likely not very difficult. If equally shared among community members, the required labour to maintain the community garden is also not particularly burdensome. Orphaned children benefiting from this garden can also be involved in its upkeep, enabling them to learn important food production skills and agricultural techniques they can use to sustain themselves in the future. A communal garden not only unites community members for a common cause, but also transfers important knowledge and skills to orphaned children who may not have benefited from their parents' knowledge about agricultural techniques prior to their deaths.

Other basic needs, such as mattresses, blankets, school fees, and scholastic materials, may be less easily catered for by the community. The most sustainable method of addressing this concern is to develop income-generating projects at the community level to raise funds for the children's needs. Depending upon the community's unique situation, a variety of projects may be developed. Common income-generating projects in this region involve raising animals, such as goats, pigs, chickens, or rabbits. Other activities generated by the community may include low-capital projects such as brick building, tailoring, cattle schemes, or various forms of craft making, such as baskets or jewellery. Caution is needed to ensure that income-generating activities do not aggravate the children's existing

problems by jeopardizing all the time and energy they need to carry out other chores and, if applicable, attend school. Witter et al propose that,

> The type of activity (non-time-intensive) must be chosen carefully, and preference given to activities where outputs and income are controlled by children, rather than by their guardians. (Witter et al, 2004, p 40)

If carefully selected and appropriately implemented, such activities can provide a valuable venue for promoting community self-sustainability, active participation in community concerns, and support for not only orphaned children but members of the community in general. This venue can be used for training community members in valuable agricultural methods, tailoring techniques, small-business development, accounting, and a multitude of other skills that can assist the community's development. If the community shows a particular interest in larger-scale approaches to income-generating projects and support for orphaned children, techniques for writing proposals for government or private funding, and skills for project development can also be imparted to the members of the community committee from LC3s or others who have experience and expertise in such areas.

The orphaned children's psychological needs also need to be addressed in the community's effort to provide support for these children. Although this usually falls under the domain of the extended family's responsibility, the reality of their limited capacity to fully support and look after the children needs to be recognized, and alternatives should be provided. The community's involvement in this is likely the next best option. This can be done without financial commitment of any kind. As part of the community committee's mandate, visiting programmes, which need not be particularly complicated, can be established. Community committees can set up visitation schedules for the orphaned children, taking turns visiting the children and checking up on them to ensure their safety and wellbeing. Although this requires the community's time, this simple act of

checking in on the children on a regular basis can provide much-needed support, encouragement, counselling, and guidance. By involving the community directly in assisting orphaned children, their envy of and discrimination towards them may be reduced as they see their own benefit in becoming involved in efforts to address their plight.

Finally, despite the adult responsibilities carried by children in child-headed households and the maturity that is required of them as they cope with circumstances that are very demanding, children in child-headed households are children nonetheless and need, at least occasionally, to be given the opportunity to behave as such. Encouraging friendships between orphaned children and others in the community could effectively enable them to integrate into their communities. Opportunities for children of child-headed households to participate in a variety of social and recreational activities, such as sports, drama clubs, choirs, and other initiatives involving young people in the community should be sought. Fostering their creativity and allowing them the space and time to release some of the stress they carry throughout their young lives is important to their physical and emotional wellbeing.

4.10.3 Government

Small-scale initiatives at the community level are instrumental in addressing the situation of child-headed households in their villages. Such efforts should be supported by, and fall within, broader initiatives that address the wider context within which child-headed households occur. The role of the government in addressing child-headed households is diverse. 'Collective solidarity' can be created through the involvement of stake-holders at multiple levels (Plan Finland, 2005). Government officials, from village leaders to federal officials, carry a responsibility to address the situation of child-headed households in Uganda. Collectively, they are faced with the task of addressing a number of issues that affect the magnitude and circumstances of orphaned children and child-headed households. These include access to education, awareness of HIV/AIDS, laws

protecting children's rights to land inheritance, and supporting NGOs and CBOs. LC1s can provide physical protection against intruders, thieves, and those intending to abuse children in child-headed households, and support children when they need assistance in dealing with their family members, other members of the community, or their schools.

Education

In addition to Universal Primary Education in Uganda, which has had a measurable effect on children's access to education as evidenced by increased enrolment rates, Universal Secondary Education should also be provided to enable every eligible child in the country to attend school. While this is under consideration, efforts should be made to support those most in need, particularly orphaned children and children living in child-headed households. The minimal effort immediately required by the government is to waive the required school fees for orphaned children. Other requirements for attending school, such as uniforms, shoes, books, and pens, should also be provided for these children free of charge or at a considerable discount. School headmasters/headmistresses, administration, and teachers should sympathise with the orphaned children's circumstances and show leniency in their response to orphaned children who may arrive at school without all the necessary requirements. Sending such children home because they lack a pen or a clean uniform only exacerbates their situation as they miss out on important learning from school and feel ostracized because they live alone.

HIV/AIDS initiatives

Great strides have been made in the Ugandan government's openness about HIV over the years, resulting in reduced prevalence of infected people throughout the country. Promotion of the ABC strategy of *A*bstinence, *B*e faithful, and *C*ondom use has been identified as a key proponent of the country's success (Genuis & Genuis, 2005). In order to continue to reduce the number of infected individuals that may ultimately leave their children in child-headed households, complacency

should be discouraged and strategies to continue to reduce HIV prevalence in the country should be furthered.

The roll-out of antiretroviral treatment (ART) to HIV-positive individuals is also an important component of any successful government strategy to reduce the impact of HIV/AIDS. In this study, it was shown that a child's age can be influential in his or her capacity to cope with the difficult circumstances in which they find themselves as heads of child-headed households, increasing age tending to mitigate, at least partially, the negative effects of living in such a situation. As such, any increases in a parent's life expectancy as can be attained if antiretroviral drug regimens are administered and adhered to appropriately, will increase the age at which a child may become part of a child-headed household.

Inheritance laws

Children's rights to property inheritance in Kabarole District are reasonably straightforward.

> In Uganda, when someone dies intestate (before making a will) his/her property is shared as follows: 75% for children (whether blood or adopted), 25% for wife/husband and other dependants. If someone leaves a will, it is normally respected. He/She can leave land/estate to anyone whether a boy or a girl child (whether last or first born) or the wife and legally it is respected that way. (Rubaale, personal communication, 2006)

Widespread awareness and particularly enforcement of these laws is central to ensuring their efficacy. Children of child-headed households need support in their efforts to maintain ownership of the land they inherited from their parents. Evidence from this study suggests that supporting children's efforts to take land matters to court can effectively secure their land ownership. As such, LC1s should be educated on the proponents of these laws and be trained on how best to ensure they are obeyed within their communities. In addition, children in child-headed

households should be provided with free legal advice and aid in taking issues surrounding property inheritance and land titles to court.

Supporting Non-Governmental Organizations

The government should make an effort to actively support NGOs and CBOs that make an effort to address the situation of child-headed households in their communities. It can assist the development of community organizations by encouraging communities to come together to address issues concerning their villages and by offering logistical and material resources to facilitate their establishment in the communities. Government officials can also link orphaned children and those in child-headed households with NGOs and CBOs in their areas. At the same time, caution in the methods used by NGOs and CBOs to support orphaned children should be exercised. Such organizations should be made aware of the unintended yet potentially disruptive effects on the children's wellbeing that can result when their standard of living is raised above that of the community members around them. They should be encouraged to make meaningful efforts to include community members in their initiatives to address the situation of orphaned children and those living in child-headed households.

4.11 Study limitations

The reliability, validity, and generalizability of the results of this study are limited by a number of factors in both the quantitative and qualitative components of the study. Although efforts were made at the outset to minimize any possible limitations in the study design and throughout the process of data collection, a number of factors may bias the results of the research.

4.11.1 Self-reported data

LC1 respondents provided information about their zones' populations and the number of orphaned children and child-headed households within their jurisdictions. Although some of them maintained that they had official records of these numbers, documentation for the information they provided was not

requested as this would have been time-consuming and would likely not have significantly altered their responses. The apparent inflation of the LC1s' responses with regard to the numbers of child-headed households in their zones thus limits the validity of this study. Common sense and consultation with professors of Public Health at Makerere University in Kampala suggest that this inflation is most likely due to the LC1s' intention to receive more support if they indicate a more urgent need for assistance to orphaned children in their area. To minimize the effects of this inflation and come to a more accurate figure about the number of child-headed households in the area, a validation procedure took place. Moreover, the LC1s' responses about various matters relating to child-headed households are their own perceptions, whether or not they are objectively seen to be true.

4.11.2 Generalizability of study findings

The generalizability of these study findings to areas outside of Kabarole District can not be guaranteed. Within Uganda's 70 districts, experiences of the AIDS epidemic and levels of responses to orphaned children vary. As such, data collected in one district are not necessarily representative of the circumstances of child-headed households in other areas. For example, northern Uganda may have a considerably different situation, as the ravages of an ongoing civil war have left behind many orphaned children in that region. Moreover, the unique climate of Kabarole District, characterized by long rainy seasons and the highest amount of rainfall in Uganda annually, offers an extremely fertile growing region and hence food-growing potential. The abundance of food in this area may have the effect of increasing the capacity of child-headed households to access sufficient quantities of food for daily consumption, unlike many other regions within Uganda which are more arid and consequently less fertile. This study, which was limited to Kabarole District, thus provides a potentially biased case scenario when compared to other districts. Because of these reasons, it is not possible to confidently generalize the findings in this report to all of Uganda.

4.11.3 Cause of parents' deaths

The intent of this study was, in part, to assess the impact of HIV/AIDS in Western Uganda by examining the situation of children orphaned by the disease. With many HIV/AIDS deaths being officially recorded as deaths from other conditions (such as opportunistic infections resulting from HIV infection) and given the difficulty in accurately ascertaining the parents' cause of death, however, documentation of this was not requested and the parents' cause of death cannot be confirmed. It is possible that children who were orphaned by the death of their parents from causes other than HIV/AIDS were unintentionally and unknowingly interviewed in the study. Given the reliability of community leaders' knowledge regarding the cause of death of the parents to the children interviewed, and the considerable impact of the disease in this region, it is unlikely that this occurred.

4.11.4 Hawthorne effect

The effect of a researcher's presence on research subjects or respondents, where the participants' awareness of the researcher's objectives influences their behaviour and responses, is commonly referred to as the Hawthorne effect and is a well-documented source of potential bias in research studies (Last, 1995). In addition to the researcher's personal biases, influenced by experience and education, the sensitive nature of the topic of child-headed households being discussed amplifies these potential limitations. In sub-Saharan Africa, this effect is complicated by the difference in the researcher's and the respondents' ethnicities. Because of the researcher's Western-European background, some children may have exaggerated the vulnerability of their situations because of the desire for more support and funding the more grave the situation appears. Conversely, it is also possible that the respondents withheld information they thought would be misinterpreted by the researcher.

4.11.5 Selection bias

Respondents for interviews in child-headed households were identified through community leaders who knew of, or could find out about, the location of the

child-headed households. As a result, 20 households that were known to members of the community were used to inform the qualitative component of this study. This may bias the results of the study as it implies that the children interviewed for the study had at least some connection to an adult who was responsible for connecting them to the village leader and, subsequently, the researcher. This may have excluded child-headed households who are even more disadvantaged than those interviewed. Because of the obvious logistical difficulty in identifying such households that are unknown to village leaders and their contacts, and doing so within a short research timeframe, methods to avoid this potential selection bias could not realistically be put in place.

4.11.6 Interviewer bias

Two research assistants carried out the bulk of interviews with the LC1 respondents, at times accompanied by the researcher. Interviews with children of child-headed households were conducted by the researcher with the assistance of an interpreter. Although research assistants received identical training, individual biases may have influenced the data collection and recording methods, and hence the research findings. Given the logistical infeasibility of having one researcher conduct all 178 LC1 interviews throughout all of Kabarole District in a short timeframe and during the rainiest month of the year, such biases could not easily have been avoided. Moreover, they are likely minimal in their effect on the overall research findings.

4.12 Study strengths

This study benefited from a number of important strengths. Most importantly, the process of validating the LC1s' responses regarding the number of child-headed households in their zones contributed substantially to the accuracy of the estimates provided in this study. The use of both quantitative and qualitative methods and the involvement of a local research team are strengths from which the validity, acceptability, and success of this study benefited.

4.12.1 Validation of LC1 responses

The validation process of the LC1s' estimates of child-headed households contributed significantly to this study as it addressed one of the key research questions in this study. Without this process, estimates of child-headed households in the district may have been quite substantially inflated, leading to an overestimation of the magnitude of the problem. Although this may have benefited future attempts to access funding and resources to address the situation of child-headed households, it is in the interest of all those involved to rely on accurate data and err on the side of underestimating rather than overestimating the extent of the problem.

4.12.2 Integration of qualitative and quantitative research methods

Without the use of both quantitative and qualitative research methods, the study's objectives of assessing the prevalence of child-headed households in Kabarole District, exploring the experiences of children who are the heads of such households, and identifying support mechanisms, could not have been attained. The quantitative component of the study provided valuable estimates of the magnitude of the phenomenon of child-headed households in the district while the in-depth interviews with child heads of households added insight, complexity, and reality to that data. Through triangulation of the results from the LC1s, the child heads of households, as well as the validation process, for instance, estimates of household sizes and other interesting findings could be verified.

4.12.3 Local research team

The assistance of a local research team and the advice of local experts in the field of public health who were consulted to maximize the study's appropriateness to the local context also contributed to this study. Using local research assistants and interpreters was critical in ensuring the acceptability of the study. Their thorough understanding of the local context, including the culture, religion, and language, added to the study's capacity to be sensitive to social norms and taboos. The high acceptance of this study, which benefited from what was virtually a 100 percent

participation rate, is also likely due in large part to the use of local research assistants. Finally, the involvement of local community leaders in accessing children living in child-headed households contributed to this study.

Chapter Five: Conclusion

This study set out to document the situation of child-headed households in Uganda's Kabarole District to assess the magnitude of the phenomenon in the district, to understand their circumstances and their needs, and ultimately to provide insight into meaningful ways of addressing their situation on a community, district, and national scale. It has become glaringly apparent throughout this report that child-headed households are widespread in Kabarole District. Constituting approximately two percent of the total number of households in the district, the high prevalence of child-headed households threatens the future stability and success of the country as a whole. Uganda is at risk of losing potentially important future leaders and facing economic, social, and political upheaval as a generation of orphaned children grow into adulthood.

At an individual level, it is clear that children living in child-headed households are severely challenged with the problems they face on a daily basis, yet they show considerable resilience and strength in coping with their circumstances. Their most urgent needs include food, housing / shelter, bedding, education, and emotional support. Support from communities, the district, and the government has been grossly inadequate. Strategies for assisting such children are not beyond the country's capacity, however. Strengthened support from the children's extended family, community, and government are necessary.

5.1 Impact of Study

At the time of writing, several initial impacts that have resulted from the data collection process and the dissemination of preliminary study findings can be identified. During the process of collecting data for this study, 181 LC1 participants (three of them in the piloting process and the remaining 178 during official data collection) were consulted. This in itself demonstrated to the LC1s that the issue of child-headed households in Kabarole District is of sufficient urgency to be investigated by researchers from outside Uganda. By participating

in this study, these village leaders were also implicitly encouraged to consider the situation of child-headed households in their regions, at a minimum bringing it to their attention and encouraging them to consider how they may play a role in addressing the children's circumstances.

Throughout the process of looking for and identifying the LC1 of each zone, countless villagers were sporadically involved in giving directions and leading the researchers to the individuals who were sought for interviewing. This may have raised awareness among the community about the importance of addressing the situation of child-headed households, as outsiders from Fort Portal town and Canada showed an interest in their circumstances.

A number of village leaders were also involved in the identification of child-headed households in their areas. As they were responsible for locating households that were headed by children, they are by necessity now aware of the precise location of these children's homes in their villages and may have some basic understanding of those children's situations. This is valuable in that it makes a connection between children in child-headed households and important members of the community who may, in the long run, be influential in channelling support to those children.

Materially, the children interviewed in this study have benefited from donations of gifts such as mattresses, blankets, and clothing that were provided to them from a sponsoring agency and others. Although this does not solve any long-term issues, it caters to some of the children's most immediate needs and hopefully enables them to be more comfortable in their sleep and be able to better function during the day. A locally-developed NGO in Fort Portal has also shown interest in becoming involved with the cause of supporting children in child-headed households as a result of this study. All respondents who had not been connected to an NGO at the time of the interviews have now been placed into contact with this NGO. So far, several of the families that participated in the study have been

visited by the NGO, and some of them have received goods such as school materials, clothing, and food. One of the families has begun a brick-building projected with the support of this NGO. In addition, through the process of disseminating preliminary research findings, a number of individuals in Canada have become interested in assisting the children living in child-headed households. Two respondents have received sponsorship for secondary school, one family has received two goats, and financial support is being sent to Fort Portal to pay for more goats and other necessities for the research respondents.

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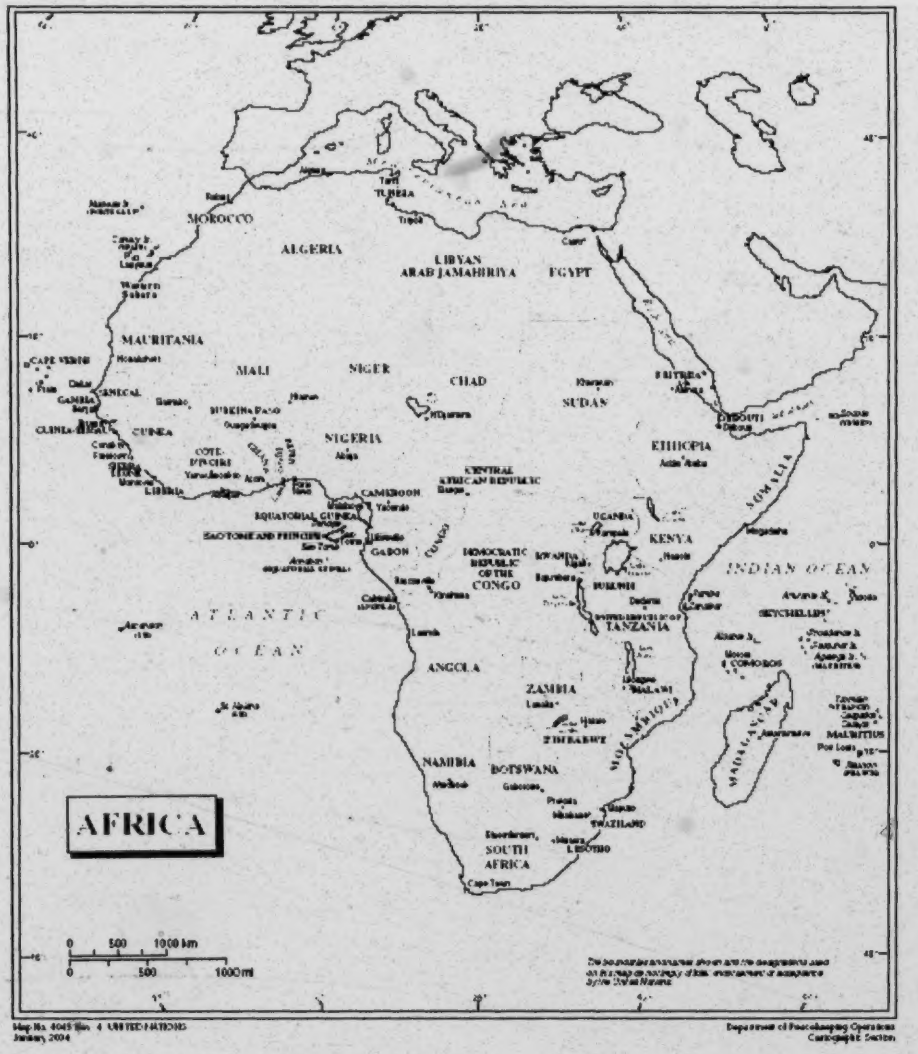
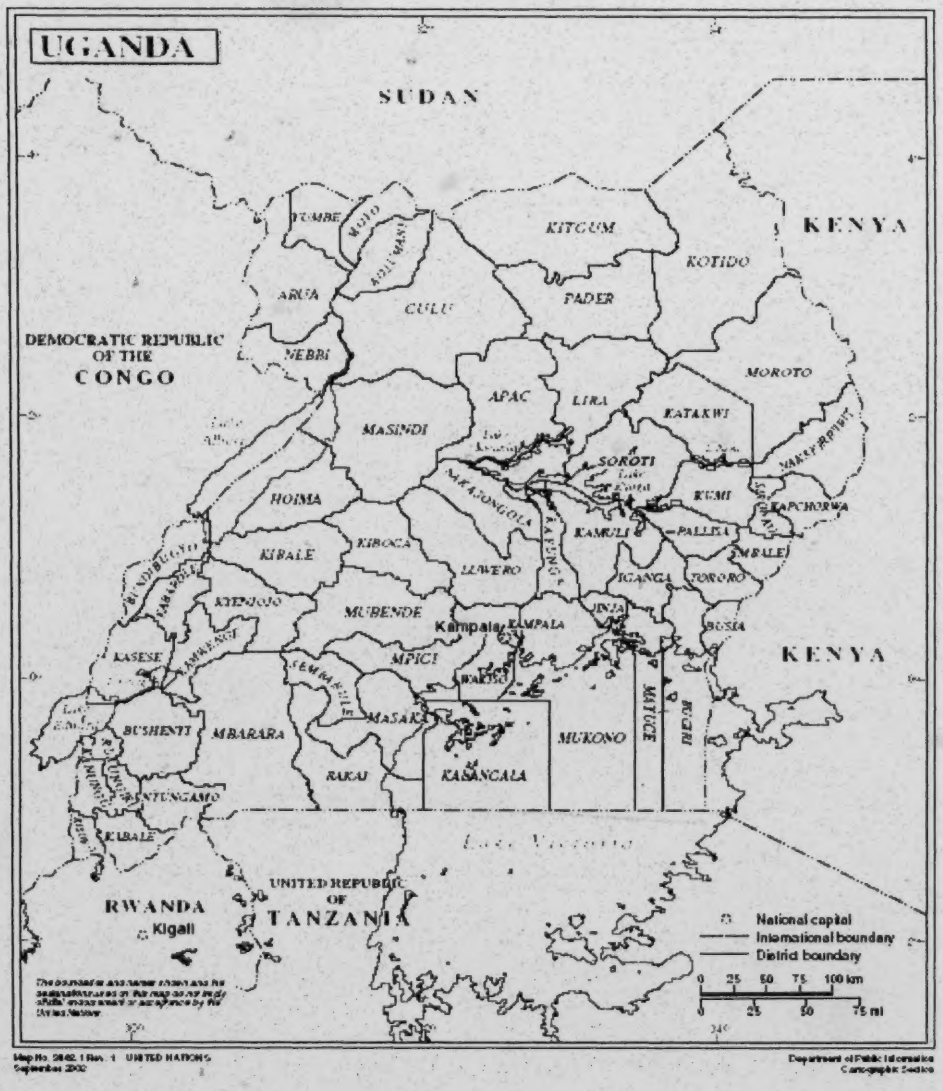
5.3 Appendices

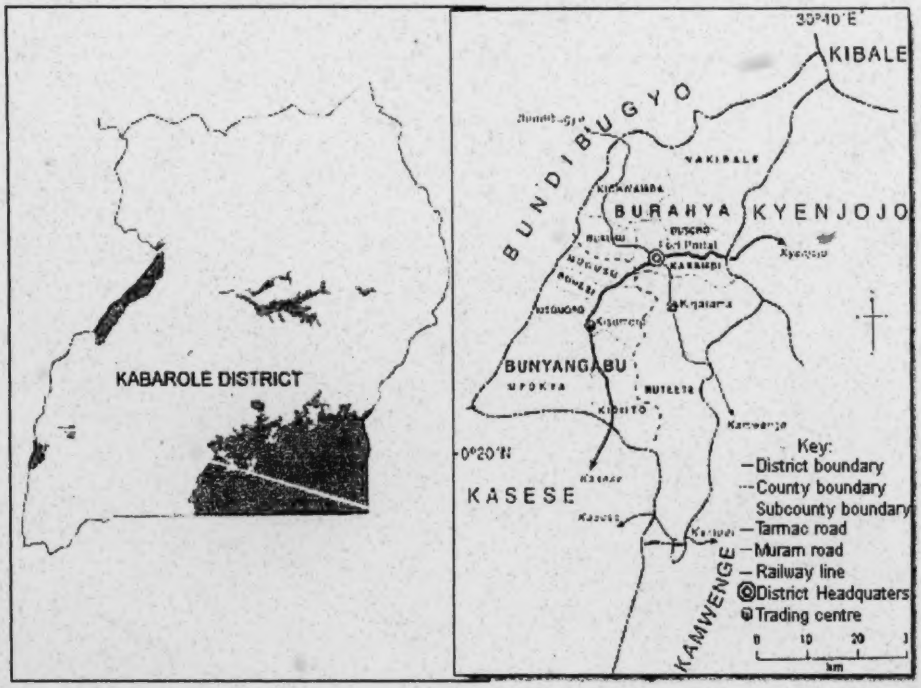
Appendix I: Map of Africa



Appendix II: Map of Uganda



Appendix III: Map of Kabarole District



Source: Kabarole District Information Portal, 2006.

Appendix IV: Introduction Letter for the Chief Administrative Officer, Kabarole District

KABAROLE DISTRICT
MEDICAL DEPARTMENT

P.O. BOX 38
FORT PORTAL

IN ANY CORRESPONDENCE ON
THIS SUBJECT PLEASE QUOTE No: 204

Tel: 00256 483 22575
Fax: 00256 483 22743

September 16 2005

The Chief Administrative Officer
Kabarole District

Dear Sir,

RE: PROPOSED STUDY ON CHILD-HEADED HOUSEHOLDS

A study on child-headed households is due to be conducted in Kabarole District over the period September-December 2005 by a graduate student named Franziska Satzinger, from the University of Alberta, Canada. Kabarole District has been collaborating with the University of Alberta for a number of years. This study will assist the District to access information that will be used in future initiatives to assist children who are heads of households. Data collection will take place in Fort Portal and in selected sub-counties throughout Kabarole District. Permission to conduct this study has been granted by the relevant bodies, including the National Council of Science and Technology.

The Kabarole District Medical Department will coordinate this study. Please address any inquiries regarding this research to the Department.

Sincerely,

Geoffrey Kabagambe
District Director of Health Services
Kabarole Medical Department
Cc: District Chairperson
Resident District Commissioner
Mayor, Fort Portal Municipality
LC3 Chairpersons

Appendix V: Introduction Letter for LC1 Participants

KABAROLE DISTRICT
MEDICAL DEPARTMENT

P.O. BOX 38
FORT PORTAL

IN ANY CORRESPONDENCE ON
THIS SUBJECT PLEASE QUOTE No: 163/5

Tel: 00256 483 22575
Fax: 00256 483 22743

September 16, 2005.

Dear LC1 Chairman, _____

We are introducing Franziska Satzinger, a Master of Science student from the University of Alberta, Canada. Ms. Satzinger is conducting a research study in Kabarole District on the situations of children living in households without adults in the home (that is, child-headed households). The study will contribute valuable information to our project, as we are interested in finding ways to better support children living in such situations. The information from this study will be used in the practical implementation of intervention programs to mitigate the social impact of HIV/AIDS.

For the purposes of data collection, Ms. Satzinger will be conducting several surveys with LC1 Chairmen throughout Kabarole District. In addition, she will conduct in-depth interviews with a number of child heads of households in and around Fort Portal town. All subjects will be advised of the nature of their proposed participation in the study and full consent will be obtained from each participant prior to beginning any interviews. Please cooperate with Ms. Satzinger and do not hesitate to contact us should you have any questions or concerns about the study.

Sincerely,

Dr. Geoffrey Kabagambe
District Director of Health Services
Kabarole Medical Department

Appendix VI: Information Letter for LC1 Participants (English)

INFORMATION LETTER FOR LC1 CHAIRPERSONS

Franziska Satzinger, Principal Investigator
Masters of Science Student, Global Health
Department of Public Health Science, University of Alberta, Edmonton, AB
Phone 078758608

Dr. Walter Kipp, Supervisor
Professor, Department of Public Health Sciences
University of Alberta, Edmonton
Phone +1.780.492.8643
Re: Child-Headed Households: Children Living the Consequences of HIV/AIDS in Western Uganda

Study purpose: We are doing a study to find out about the situations of children who are living in homes without parents or guardians because their parents have died of AIDS. This will help us to discover the most important needs of these children and their sources of resources and support.

What is involved: If you agree to participate in the study, you will be asked some questions about the numbers and situations of households headed by children in your area. You will be asked to identify some of the main issues such children are faced with, and to explain how the community is reacting to the issue of child-headed households. In addition, some questions will ask about how much and what kind of support is available for children living in such circumstances. The questions will be asked in your choice of Rutooro or English, and the interview should take approximately 20 minutes.

Risks and Benefits: There are no known risks from participating in this study.

Confidentiality: Your name will not be used in the study. Only the research assistant and the Principal Investigator will be able to access the information that we collect today. If we publish or present the findings of this study, we will not use your name.

Freedom to withdraw: Participation in this study is voluntary. If you decide to participate, you may tell the interviewer at anytime that you wish to stop the interview. You do not need to answer any questions you do not want to answer.

Questions or concerns: If you have any questions about this study, you can call the Principal Investigator at 078758608 or Mr. Tom Rubaale at the Health Department in Fort Portal at 078856865.
Initial of Researcher..... Initial of Informant.....

Appendix VII: Information Letter for Child-Headed Households Participants (English)

INFORMATION LETTER FOR PARTICIPANTS

Franziska Satzinger, Principal Investigator
Masters of Science Student, Global Health
Department of Public Health Science, University of Alberta, Edmonton, AB
Phone 078758608

Dr. Walter Kipp, Supervisor
Professor. Department of Public Health Sciences
University of Alberta, Edmonton
Re: Child-headed households: Children Living the Consequences of HIV/AIDS in Western Uganda

Study purpose: We are doing a study because we want to know what life is like for children living without parents. We want to find out what you need. We also want to find out how you get by without parents.

What is involved: If you want to be part of this study, we will ask you some questions. We will ask you to tell us how old you are, and how many brothers and sisters you have. We will talk about how you how you get money for things like food, soap, and transportation. We may ask you what happens when you or one of your brothers or sisters falls ill. Then we will talk about your education. We will ask about how much help you are getting from other relatives or people in the community. We can ask you all the questions in your language, and you may also answer in your language. This should take about 30 minutes.

Risks and Benefits: You may feel shy about answering some of the questions we ask. You may also feel upset by talking about your situation. If this happens, you can tell us to stop the interview. We will also have someone from your community available for you to talk to if you are upset. Apart from this, we do not know of any other things you might dislike about being part of the study.

Confidentiality: We will not use your name in this study. Only the researcher and the interpreter will be able to see the information that we collect today. If we write about or tell other people about what you tell us, we will never use your names, so people will not know that you told us.

Freedom to withdraw: If you do not want to be in this study, you do not have to be in it. When we are talking with you, if you decide you do not want to be in the study anymore, you can tell us and we will stop the interview. You do not need to answer any questions you don't want to answer.

Questions or concerns: If you have any questions about this study, you can call Franziska Satzinger at 078758608, or Mr. Tom Rubaale at the Health Department in Fort Portal at 078856865.

Appendix VIII: Consent form for LC1 Participants (English)

CONSENT FORM FOR PARTICIPANTS

Social Impact of HIV/AIDS in Western Uganda: Children as Parents **Part 1: Researcher Information**		
Name of Principal Investigator: Franziska Satzinger Affiliation: University of Alberta Contact Information: 078758608		
Name of Co-Investigator/Supervisor: Dr. Walter Kipp Affiliation: University of Alberta Contact Information: 1.780.492.8643		
Part 2: Consent of Subject		
	Yes	No
Do you understand that you have been asked to be in a research study?		
Have you read and received a copy of the attached information letter?		
Do you understand the benefits and risks involved in taking part in this research study?		
Have you had an opportunity to ask questions and discuss the study?		
Do you understand that you are free to refuse to participate or withdraw from the study at any time? You do not have to give a reason.		
Has the issue of confidentiality been explained to you?		
Do you understand who will have access to your records/information?		
Do you agree to allow the researcher to write down your responses?		
Do you agree to be contacted by the researcher and/or the Principal Investigator at a later date for follow-up, if necessary?		
Part 3: Signatures		
This study was explained to me by: _____ Date: _____		
I agree to take part in this study. Signature of Research Participant: _____ Printed Name: _____		
Witness (if available): _____ Printed Name: _____		

Appendix IV: Consent form for Child-Headed Households Participants (English)

CONSENT FORM FOR PARTICIPANTS

Social Impact of HIV/AIDS in Western Uganda: Children as Parents Part 1: Researcher Information		
Name of Principal Investigator: Franziska Satzinger Affiliation: University of Alberta Contact Information: 078758608		
Name of Co-Investigator/Supervisor: Dr. Walter Kipp Affiliation: University of Alberta Contact Information: 1.780.492.8643		
Part 2: Consent of Subject		
	Yes	No
Do you understand that you have been asked to be in a research study?		
Have you read and received a copy of the attached information letter?		
Do you understand the benefits and risks involved in taking part in this research study?		
Have you had an opportunity to ask questions and discuss the study?		
Do you understand that you are free to refuse to participate or withdraw from the study at any time? You do not have to give a reason.		
Has the issue of confidentiality been explained to you?		
Do you understand who will have access to your records/information?		
Do you agree to allow the researcher to audiotape and/or write down your responses?		
Do you agree to be contacted by the researcher and/or the Principal Investigator at a later date for follow-up, if necessary?		
Part 3: Signatures		
This study was explained to me by: _____ Date: _____		
I agree to take part in this study. Signature of Research Participant: _____ Printed Name: _____		
Witness (if available): _____ Printed Name: _____		

Appendix X: Survey Questionnaire for LC1 Participants (English)

SURVEY
(ENGLISH)

Child-Headed Households
Kabarole District

LC1 Chairpersons

RESPONDENT I.D. NUMBER_____

DIVISION (SUB-COUNTY) _____

PARISH _____

VILLAGE/ZONE/LC1 _____

LC1 CHAIRMAN NAME _____

LC1 CHAIRMAN PHONE _____

INTERVIEWER NAME _____

COMPLETION TIME START TIME _____ END TIME _____

DATE _____

SURVEY CHECKED BY: _____
CO-INVESTIGATOR

DATA ENTRANT 1:_____ DATE: _____

DATA ENTRANT 2:_____ DATE: _____

No.	Questions and filters	Coding Categories	Comments
1	For how many years have you been Chairman of this LC1?	0 – 2 years.....1 3 – 5 years.....2 6 – 8 years.....3 9+ years.....4	**Immediately , go to (8) and circle either "five" or "ten".**
2	What is the total population of the village for which you are LC1 Chairman?	_____	
3	In your opinion, what is the definition of an orphaned child?	Death of father *or* mother.....1 Death of father *and* mother.....2 Other.....3 Specify_____	
4	In your village, how many children do you estimate are orphaned?	_____	
5	In total, how many households in your village do you estimate are headed by orphaned children of age 18 years or younger?	_____	
6	How many of these households you have just mentioned consist of children who have lost their parents to HIV/AIDS?	_____	
7	On average, how many children live in each child-headed household?	1 – 3 children.....1 4 – 6 children.....2 7 – 9 children.....3 10+ children.....4	
8	In your understanding, has the total number of child-headed households in your area increased, decreased or remained the same over the last five / ten years?	Increased.....1 Decreased.....2 Remained the same.....3 Don't know.....4 Other.....5 Specify_____	

9	What are the most urgent problems faced by children living in child-headed households? **[Unprompted, circle all that apply]**	Housing / shelter.....1 Food.....2 School fees.....3 School materials.....4 Clothing.....5 Bedding.....6 Cooking facilities.....7 Diseases / infections.....8 Access to medical treatment.....9 Discrimination / stigma.....10 Neglect own health / no time for self.....11 Loss of land / property grabbing...12 Poverty.....13 Other.....14 Specify_____	
10	What are the most effective support systems to assist these children? **[Unprompted, circle all that apply]**	Extended family .....1 Neighbours.....2 Community workers / social workers.....3 NGOs / local organizations.....4 Government initiatives.....5 Healthcare workers (nurses, doctors, counsellors, home-based care).....6 Church / religion.....7 LC1s / Community leaders.....8 Other.....9 Specify_____	
11	In your opinion, what responsibility should the LC1s have in supporting child-headed households? **[Unprompted, circle all that apply]**	Directly (pay school and/or medical fees).....1 Indirectly (support local organizations).....2 Public awareness.....3 Mobilize the community.....4 No responsibility.....5 Other.....6 Specify_____	
12	What can the government do to support *informal* support structures that assist child-headed households, such as extended family, neighbours, or friends? **[Unprompted, circle all that apply]**	Financial assistance to supporters...1 Community support groups for supporters.....2 Visiting programme.....3 Housing / rehabilitation facilities...4 Food aid.....5 Income-generating projects.....6 Other.....7 Specify_____	
13	What obstacles stand	Finances.....1	

	in the way of efforts to assist children living in child-headed households? **[Unprompted, circle all that apply]**	Lack of awareness.....2 Discrimination / stigma.....3 Lack of personnel.....4 Don't care attitude / indifference...5 Poor infrastructure / accessibility...6 Other.....7 Specify_____	
14	If we compare children living in child-headed households to children who live with parents or caregivers, do the children in the child-headed households have a better, worse, or the same chance of being able to attend school as the other children?	Worse chance.....1 Better chance.....2 Same chance.....3 Other.....4 Specify_____	**If (2), skip question 15.**
15	What would be the most effective way to assist children from child-headed households to children to continue to attend school? **[Unprompted, circle all that apply]**	Relatives/friends pay fees.....1 Outside sponsors pay fees.....2 Community organizations pay fees.3 Government programme pays fees..4 Income-generating projects.....5 Lessen their burden at home.....6 Other.....7 Specify_____	
16	How has the community responded to the situation of child-headed households in your village?	Positive, active involvement.....1 Not aware, no involvement.....2 Negative, no involvement.....3 Involvement, but not enough.....4 Other.....5 Specify_____	
17	Can you give us the name of any programme or organization in your village that assists children living in child-headed households?	Organization_____ Contact Name_____ Phone_____	
18	What hope do you think there is that the situation will improve for children living in child-headed	Little hope, situation may worsen....1 Little hope, situation will remain same.....2 Some hope, situation may improve...3 Much hope, situation will improve...4	

	households in Kabarole District?	Other.....5 Specify_____	
19	How do you think the future of the country will be affected as a result of this situation of children growing up without parental guidance or support? **[Unprompted, circle all that apply]**	No school, no employment.....1 No nurturing / caretaking abilities....2 Poor health, burden on system.....3 Few social skills, no integration.....4 Poor upbringing, ill-behaved.....5 Prostitution, crime.....6 HIV/AIDS and STIs increase.....7 Perpetuates cycle of poverty.....8 Political/economic/social upheaval...9 Other.....10 Specify_____	

ADDITIONAL COMMENTS:

_____

_____

_____

_____

_____

_____

_____

_____

Thank you very much for your time and for participating in this survey today. We appreciate your input. Please feel free to contact us at the phone numbers given, if you have any further questions or concerns about the study.

Appendix XI: Questions for Unsupported Child-Headed Households Participants

IN-DEPTH INTERVIEWS

Child-Headed Households
Kabarole District

HEADS OF HOUSEHOLDS
[Unsupported]

RESPONDENT I.D. NUMBER _____

PARISH _____

VILLAGE _____

HEAD OF HOUSEHOLD NAME _____

HEAD OF HOUSEHOLD CONTACT _____

CONTACT PERSON NAME _____

CONTACT PERSON CONTACT _____

INTERVIEWER NAME _____

INTERPRETER NAME _____

COMPLETION TIME START TIME _____ END TIME _____

DATE _____

AUDIORECORDER NAME _____

RECORDING TITLE GIVEN _____

RECORDING TRANSCRIBED BY _____

RECORDING TRANSFERRED TO COMPUTER ON _____

TRANSLATION BY _____

BACK TRANSLATION BY _____

Demographics

No	Questions and filters	Prompts	Comments
1	**Observe: Sex of head of household (participant)**		
2	**Observe: Type of housing**	Permanent (concrete)? Semi-permanent (mud/wattle, iron roof)? Temporary (grass thatched, grass or mud walls)?	
3	**Observe: SES assessors**	Radio? TV? Bicycle? Animals? Refrigerator? Motorcycle? Land?	
4	What is your name?	How old are you? Are you the oldest child in this household?	
5	How many children live in your household?	Are these children all siblings?	Cousins? Friends? Other relatives?
6	What is the age of each child in your household?		
7	How many children in the household are you responsible for / do you care for?		
8	Do you have other siblings who do not live with you?	Where do they live? Do they visit you sometimes? How often?	
9	For how long have you been living without a parent/adult in the household?		
10	When your parent(s) were living, did you ever talk about what may happen (i.e. what you should do) after their death?	Was there a plan for someone in particular to care for you or for you to go to if you are in need of assistance? Is this person assisting you in any way? How? Why or why not?	

11	Do you have other relatives?	Why are you not living with them?	
12	Between the death of your parent(s) and now, have you lived with other relatives? For how long? Where? Which relative?	Why are you no longer living with them? What happened?	

School Attendance

13	Who (of the children in the household) is attending school?		
14	How are the school fees, uniforms, and supplies paid?		
15	Please tell me what level of school each child in this household is in or has most recently completed.		
16	**[If applicable]** When you go to school without uniform, school materials, and/or no food or money for food, what happens?	Do you get sent home? Does someone pay for your lunch?	
17	**[If any child at Secondary level or entering Secondary level]** How do you expect to pay for secondary school fees next year?		
18	**[If any child attending school]** Do you feel you are discriminated against at school? At home?	Who discriminates against you? (Teachers? Fellow students? Administration?) (Aunts, uncles, neighbours)? How do they discriminate against you (i.e. what do they do)?	

Income

19	Who is the breadwinner in this household?	Where does the income come from? Do you (does the breadwinner) have a job? What is the job? Where? How often? Is the employment secure (i.e. do you think you will have the job for quite some time, or is it temporary?)	
20	**[If no one in the household has a job]** When you need things like soap, sugar, posho, or salt, how do you get these things?	What money do you use to purchase these things? Does someone give these items to you? Who? How often?	
21	Do you have any: Land? Garden/cultivatable land? Animals?	Land? Is this your parents' land? **[If no]:** Whose land are you living on? What happened to your parents' land? Animals? Can these animals sustain you? What do you get from them (i.e. milk, eggs, meat)? Garden / cultivatable land? How much food do you get from it? During what seasons?	
22	Do you get financial support from family members, friends, neighbours, well-wishers or LC1 chairmen?		
23	**[If other siblings not living in CHH]** You mentioned you have a brother/sister who does not live with you. Does s/he support you in any way?	How?(What kind of support)? How often? Can you call on him/her if you are in need? Why do you think s/he is no longer living with you?	

24	Do you receive any assistance from others?	Who assists you? What do they assist you with? How do they help you? How often do they help you? When was the last time they helped you? Why do you think they are helping you?	

Water, Sanitation & Cooking

25	Do you have access to safe water (i.e. water that you can drink without getting ill)?	Who collects the water? From where do you get this water? How far is it from here? How often do you get it?	
26	What do you use for cooking?	Firewood? Charcoal? From where do you get the materials for cooking? How often do you have to collect/buy them?	
27	**Observations:** **Toilet?** **Waste?** **Sewage?**		

Clothing & Bedding

28	Observe: Clothing **[NB: Might be dressed differently because of interview]**		
29	Do you and your siblings have clothing that will keep you warm in the colder, rainier times of the day or year?	From where do you get your clothing? What will you do if you need warmer clothing (a coat, trousers) for you or your siblings?	
30	**Observe: Sleeping situation**	Mattress(es)? How many? Share the mattress(es)? Blankets? How many? Enough?	

Health – Adequacy of Food Intake

31	How many times do you eat each day?		
32	Please describe for me what you regularly take in the morning, at midday, and in the evening.		
33	From where do you get this food?	Do you grow it yourself? Buy it from the market? Do others bring it for you? Who? How often?	
34	Is there enough food to feed everyone in the household?	If not, what do you do? (I.e. does someone go hungry? Who?)	
35	**Observe: Any stored food (i.e. maize)**	For how much time will this food last? What will you do when the food runs out?	
36	**Observe: Are children stunted? Wasted? Malnourished?**		

Health – Known Health Problems

37	Do you know of any health problems that you or your siblings have? Do you have: Diarrhea? Chronic headaches? Cough? Fever / malaria? Wounds or other skin problems? Worms?	For how long have you felt these symptoms? What have you been doing to help with these symptoms? Have you had any of these problems in the last six months? Twelve months? Do you feel better now? The same? Getting worse?	
38	How does this illness affect your everyday life (i.e. chores, school etc)?		
39	Where do you go for health services / treatment if you or your sibling falls ill?	Do you pay for treatment or is it free? Does someone else pay for you? Who?	

40	Are you immunized?	What diseases are you immunized against?	
41	Were you immunized before the death of your parents, or have you received immunizations since the time they died?	How did you know that you should get the immunizations?	
42	Where did you get immunized?	Did you pay for the immunizations? Who paid?	

Social Effects

43	Do you find that other people in the community treat you differently now that you are living on your own?		Stigma? Avoidance? Discriminati on? Fear?
44	Do you feel you are stigmatized because of being poor? Because of being in a child-headed household? Because of AIDS?		
45	How do you feel being the head of a household?	Is it too much responsibility for you? Do you feel angry that you are missing your childhood / adolescence?	

Psychological Effects

46	How do you feel without having parents?	How are you coping with this?	
47	Is there anything you are afraid of?		
48	Do you feel angry or lonely at times?		
49	What are your thoughts about the future?	Are you hopeful things will improve? What helps you to get through each day? What do you think it is about you that helps you to cope with all the	Good behaviour? Out of necessity / no choice?

		responsibilities you have?	
50	What do you hope for in the future?	What would you like your future to look like?	
51	Do you have personal goals that you would like to achieve in the future?	What are these goals? What would help you achieve these goals?	
52	Would you prefer to live in an institution (children's home, orphanage) instead of where/how you are living now?	Why / why not?	

Support

53	Do you receive any financial support from anyone?	From whom? How do they support you?	
54	Is there someone who you can talk to when you need emotional support or are feeling sad or lonely?	How do they support you? How often do you see them?	
55	How have you learned to take on the responsibility of parenting your siblings?	How do you know how to take care of your siblings? How have you learned to do things like cooking, cleaning, tending to the garden etc?	
56	What do you find to be the most difficult part of taking care of your siblings and the household?		
57	Do you feel that your siblings treat you with respect as a parent?	Do you find it difficult to guide them and instill good behaviour in them?	
58	Before your parents died, what role did you play in taking care of them when they were ill?	How was that for you?	
59	At the moment, what are your most urgent needs?		

60	If you could ask your community to assist you in some way, what would you ask them to do for you?	What would help you the most? What could any remaining relatives do to assist you now?	
61	Do you think the government has done enough for you in your situation?	How could the government best help you?	

Appendix XI: Questions for Supported Child-Headed Households Participants

IN-DEPTH INTERVIEWS

Child-Headed Households
Kabarole District

HEADS OF HOUSEHOLDS
[Supported]

RESPONDENT I.D. NUMBER_____

PARISH _____

VILLAGE _____

HEAD OF HOUSEHOLD NAME _____

HEAD OF HOUSEHOLD CONTACT _____

CONTACT PERSON NAME _____

CONTACT PERSON CONTACT _____

INTERVIEWER NAME _____

INTERPRETER NAME _____

COMPLETION TIME START TIME _____ END TIME _____

DATE _____

AUDIORECORDER NAME _____

RECORDING TITLE GIVEN _____

RECORDING TRANSCRIBED BY _____

RECORDING TRANSFERRED TO COMPUTER ON _____

TRANSLATION BY _____

BACK TRANSLATION BY _____

Demographics

No	Questions and filters	Prompts	Comments
1	**Observe: Sex of head of household (participant)**		
2	**Observe: Type of housing**	Permanent (concrete)? Semi-permanent (mud/wattle, iron roof)? Temporary (grass thatched, grass or mud walls)?	
3	**Observe: SES assessors**	Radio? TV? Bicycle? Animals? Refrigerator? Motorcycle? Land?	
4	What is your name?	How old are you? Are you the oldest child in this household?	
5	How many children live in your household?	Are these children all siblings?	Cousins? Friends? Other relatives?
6	What is the age of each child in your household?		
7	How many children in the household are you responsible for / do you care for?		
8	Do you have other siblings who do not live with you?	Where do they live? Do they visit you sometimes? How often?	
9	For how long have you been living without a parent/adult in the household?		
10	When your parent(s) were living, did you ever talk about what may happen (i.e. what you should do) after their death?	Was there a plan for someone in particular to care for you or for you to go to if you are in need of assistance? Is this person assisting you in any way? How? Why or why not?	

11	Do you have other relatives?	Why are you not living with them?	
12	Between the death of your parent(s) and now, have you lived with other relatives? For how long? Where? Which relative?	Why are you no longer living with them? What happened?	

School Attendance

13	Who (of the children in the household) is attending school?		
14	How are the school fees, uniforms, and supplies paid?		
15	Please tell me what level of school each child in this household is in or has most recently completed.		
16	**[If applicable]** When you go to school without uniform, school materials, and/or no food or money for food, what happens?	Do you get sent home? Does someone pay for your lunch?	
17	**[If any child at Secondary level or entering Secondary level]** How do you expect to pay for secondary school fees next year?		
18	**[If any child attending school]** Do you feel you are discriminated against at school? At home?	Who discriminates against you? (Teachers? Fellow students? Administration?) (Aunts, uncles, neighbours)? How do they discriminate against you (i.e. what do they do)?	

Income

19	Who is the breadwinner in this household?	Where does the income come from? Do you (does the breadwinner) have a job? What is the job? Where? How often? Is the employment secure (i.e. do you think you will have the job for quite some time, or is it temporary?)	
20	**[If no one in the household has a job]** When you need things like soap, sugar, posho, or salt, how do you get these things?	What money do you use to purchase these things? Does someone give these items to you? Who? How often?	
21	Do you have any: Land? Garden/cultivatable land? Animals?	Land? Is this your parents' land? [If no]: Whose land are you living on? What happened to your parents' land? Animals? Can these animals sustain you? What do you get from them (i.e. milk, eggs, meat)? Garden / cultivatable land? How much food do you get from it? During what seasons?	
22	Do you get financial support from family members, friends, neighbours, well-wishers or LC1 chairmen?		
23	**[If other siblings not living in CHH]** You mentioned you have a brother/sister who does not live with you. Does s/he support you in any way?	How? (What kind of support)? How often? Can you call on him/her if you are in need? Why do you think s/he is no longer living with you?	

24	Do you receive any assistance from others?	Who assists you? What do they assist you with? How do they help you? How often do they help you? When was the last time they helped you? Why do you think they are helping you?	

Water, Sanitation & Cooking

25	Do you have access to safe water (i.e. water that you can drink without getting ill)?	Who collects the water? From where do you get this water? How far is it from here? How often do you get it?	
26	What do you use for cooking?	Firewood? Charcoal? From where do you get the materials for cooking? How often do you have to collect/buy them?	
27	**Observations:** **Toilet?** **Waste?** **Sewage?**		

Clothing & Bedding

28	**Observe:** **Clothing** **[NB: Might be dressed differently because of interview]**		
29	Do you and your siblings have clothing that will keep you warm in the colder, rainier times of the day or year?	From where do you get your clothing? What will you do if you need warmer clothing (a coat, trousers) for you or your siblings?	
30	**Observe: Sleeping situation**	Mattress(es)? How many? Share the mattress(es)? Blankets? How many? Enough?	

Health – Adequacy of Food Intake

31	How many times do you eat each day?		
32	Please describe for me what you regularly take in the morning, at midday, and in the evening.		
33	From where do you get this food?	Do you grow it yourself? Buy it from the market? Do others bring it for you? Who? How often?	
34	Is there enough food to feed everyone in the household?	If not, what do you do? (I.e. does someone go hungry? Who?)	
35	**Observe: Any stored food (i.e. maize)**	For how much time will this food last? What will you do when the food runs out?	
36	**Observe: Are children stunted? Wasted? Malnourished?**		

Health – Known Health Problems

37	Do you know of any health problems that you or your siblings have? Do you have: Diarrhea? Chronic headaches? Cough? Fever / malaria? Wounds or other skin problems? Worms?	For how long have you felt these symptoms? What have you been doing to help with these symptoms? Have you had any of these problems in the last six months? Twelve months? Do you feel better now? The same? Getting worse?	
38	How does this illness affect your everyday life (i.e. chores, school etc)?		
39	Where do you go for health services / treatment if you or your sibling falls ill?	Do you pay for treatment or is it free? Does someone else pay for you? Who?	

40	Are you immunized?	What diseases are you immunized against?	
41	Were you immunized before the death of your parents, or have you received immunizations since the time they died?	How did you know that you should get the immunizations?	
42	Where did you get immunized?	Did you pay for the immunizations? Who paid?	

Social Effects

43	Do you find that other people in the community treat you differently now that you are living on your own?		Stigma? Avoidance? Discrimination? Fear?
44	Do you feel you are stigmatized because of being poor? Because of being in a child-headed household? Because of AIDS?		
45	How do you feel being the head of a household?	Is it too much responsibility for you? Do you feel angry that you are missing your childhood / adolescence?	

Psychological Effects

46	How do you feel without having parents?	How are you coping with this?	
47	Is there anything you are afraid of?		
48	Do you feel angry or lonely at times?		
49	What are your thoughts about the future?	Are you hopeful things will improve? What helps you to get through each day? What do you think it is about you that helps you to cope with all the	Good behaviour? Out of necessity / no choice?

		responsibilities you have?	
50	What do you hope for in the future?	What would you like your future to look like?	
51	Do you have personal goals that you would like to achieve in the future?	What are these goals? What would help you achieve these goals?	
52	Would you prefer to live in an institution (children's home, orphanage) instead of where/how you are living now?	Why / why not?	

Support

53	Do you receive any financial support from anyone?	From whom? How do they support you?	
54	How did you come into contact with the supporters?	Do you think you can count on this support to be there for a while?	
55	What is most helpful about the support you receive?	How is your life/situation different now as a result of receiving this support?	
56	Is there someone who you can talk to when you need emotional support or are feeling sad or lonely?	How do they support you? How often do you see them?	
57	How have you learned to take on the responsibility of parenting your siblings?	How do you know how to take care of your siblings? How have you learned to do things like cooking, cleaning, tending to the garden etc?	
58	What do you find to be the most difficult part of taking care of your siblings and the household?		
59	Do you feel that your siblings treat you with respect as a parent?	Do you find it difficult to guide them and instill good behaviour in them?	
60	Before your parents died, what role did	How was that for you?	

	you play in taking care of them when they were ill?		
61	At the moment, what are your most urgent needs?		
62	If you could ask your community to assist you in some way, what would you ask them to do for you?	What would help you the most? What could any remaining relatives do to assist you now?	
63	Do you think the government has done enough for you in your situation?	How could the government best help you?	